Who cares?

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Research into maintaining, strengthening, and expanding the informal social networks of people with profound intellectual and multiple disabilities

Aafke Kamstra

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Content

Chapter 1

Introduction

In research on people with intellectual disabilities (ID), the topic of social networks features in both scientific discussions and practical initiatives. This is not surprising, considering that the social domain is an important aspect of the quality of life of people with ID (Schalock & Verdugo, 2002). Furthermore, the social networks of people with ID are believed to contribute to social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle Brown, 2009; McConkey, 2007), leading to more personal freedom and autonomy (Forrester-Jones et al., 2006), and contributing to mental health (Scott & Havercamp, 2014). Social networks can be described in terms of two categories: how they are structured and what function(s) they serve (Buysse, 1997; Heaney & Israel, 2008; Lippold & Burns, 2009, Lunksy, 2006). Lunsky (2006) considers the structure of a social network as "a layout of a group of persons who give to and receive support from one another." The characteristics of a social network are: size of the network, density, homogeneity, multiplicity (the variety of functions a relationship serves), and frequency of interactions (Lunsky, 2006). In addition to its structure, a social network can serve multiple functions, which generally can be divided into emotional (expressions of love, empathy, caring, and trust) or practical (goods, services, advice, information) support (Heaney & Israel, 2008; Lunsky, 2006). What function a relationship serves is often derived from the type of contact there is between two persons. The type of people in a social network can be divided into formal (paid) contacts and informal (unpaid) contacts (Bigby, 2008; Forrester-Jones et al., 2006; Heaney & Israel, 2008). For people with ID living in a residential facility, formal contacts are uppermost in their lives (Lunsky, 2006). It is likely that those contacts mainly provide practical support. Providing emotional support usually springs from personal motives rather than employment (Bigby, 2008) and is thus more likely to be provided mainly by informal contacts.

Multiple research projects have been carried out, which study the structure and function of informal social networks of people with ID (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). These studies have shown that these informal social networks are limited in size, become smaller with aging, and mainly consist of family members and peers. Recommendations include the involvement of persons with ID when determining satisfaction with the existing informal social network and their wishes. Furthermore, teaching social skills to persons with ID and supporting them in leisure activities is recommended. It is remarkable that these research projects mainly focus on people with mild intellectual disabilities and seldom on people with severe or profound intellectual disabilities (Verdonschot et al., 2009). Even more striking is that the socially most vulnerable group of people within the group of people with ID is the one least likely to be included: people with profound intellectual and multiple disabilities (PIMD).

People with PIMD have a profound intellectual disability, with a developmental age of less than two years, combined with a severe or profound motor disability that often leaves them wheelchair-bound (Nakken & Vlaskamp, 2007). People with PIMD almost always experience sensory disabilities, mainly visual and auditory, in addition to physical health problems such as problems with eating and drinking, and hence growth problems, gastro-intestinal problems, problems with oral hygiene and dental care, sleeping problems, over or underweight, epilepsy, orthopedic problems or osteoporosis (De Cock, 2011; Maes, Lambrechts, Hostyn, & Petry, 2007; Nakken & Vlaskamp, 2007, Van Timmeren et al., 2016). These physical health problems can lead to pain (De Cock, 2011) or excessive use of medicines (polypharmacy) (Van der Heide, Van der Putten, Van den Berg, Taxis, & Vlaskamp, 2009), which, in turn, can affect, among other things, the level of alertness of people with PIMD. Furthermore, physical health problems, such as sleep and auditory problems, can be related to the exhibition of challenging behaviour (Poppes, Van der Putten, Post, & Vlaskamp, 2016). Due to the variety and severity of the disabilities seen in people with PIMD, they form a highly heterogeneous group (Zijlstra & Vlaskamp, 2005). However, people with PIMD do have one thing in common: They are highly dependent on other people in all aspects of their daily lives (Maes et al., 2007; Nakken & Vlaskamp, 2007; Vlaskamp, Poppes, & Zijlstra, 2005).

Because of the severity of their disabilities, people with PIMD experience limitations in communicating; they are almost incapable of expressing themselves verbally. People with PIMD interact on a pre- or protosymbolic level (Petry & Maes, 2006). Communication therefore mainly occurs through body movement, posture, muscle tension, facial expressions, sounds, or other cues that are personal or context-related (Hostyn & Maes, 2009; Vlaskamp et al., 2005). By deploying these communicative signals, they try to express their wishes, needs, and feelings (Vos, Cock, Petry, Van den Noortgate, & Maes, 2010). The communicative signals can be so subtle that they often go unnoticed. Given the severity of their disabilities, especially their limited and idiosyncratic abilities in terms of communication, it is questionable whether the results from studies into the informal social networks of people with ID, as mentioned earlier, can be plainly generalized to include the specific group of people with PIMD. Moreover, the implications for practice, such as how to teach them social skills, are not suitable for people with PIMD due to their disabilities.

Due to the high support and care needs of people with PIMD, the formal network is often well represented, for instance, care practitioners, therapists, or direct support persons (DSPs). It is assumed that this formal network's primary goal is to provide practical support, since a DSP has a clear job description. Furthermore, the relationship with a person with PIMD is characterized by inequality. This does

not mean that DSPs do not provide emotional support as well. However, it takes time to build a positive relationship, and this time is most often spent on the high physical care needs of the persons with PIMD. Furthermore, DSPs do not necessarily work with the same persons with PIMD for a prolonged period of time, as they change jobs or the person with PIMD moves. The emotional support provided by DSPs is usually not unconditional. Unconditional emotional support is generally provided by an informal, unpaid, network. Their involvement is based on personal motives and is not dependent on working schedules or payment. In order to be able to provide emotional support, it is important to know a person, meaning that a person with PIMD needs people in his/her life who are able to correctly interpret the communicative signals and respond accordingly, and are willing to establish a long-term caring relationship (Hostyn & Maes, 2009; Maes et al., 2007; Vlaskamp et al., 2005). These long-term caring social relationships are formed through repeated successful social interactions (Beauchamp & Anderson, 2010), which, in turn, can be seen as activities between two people, which are rewarding for both parties (Beauchamp & Anderson, 2010; Olsson, 2004; Olsson, 2005).

In general, such relationships are important for everyone; most people are looking for affectively positive interactions within the context of long-term, caring relationships (Baumeister & Leary, 1995), or positive informal relationships. People with PIMD are also in need of positive informal relationships with others (Hostyn & Daelman, 2011; Petry, Maes, & Vlaskamp, 2005). Positive informal relationships are important for several other reasons: They prevent loneliness and negative health effects (Baumeister & Leary, 1995; Cohen, 2004) and facilitate social inclusion (Abbott & McConkey, 2006; Bigby et al., 2009; Johnson, Douglas, Bigby, & Iacono, 2010; McConkey, 2007). Finally, positive informal relationships enable participation by bringing the person with PIMD into society and providing the person with PIMD with a sense of belonging (Petry et al., 2005). This makes having positive informal relationships an important aspect of the quality of life of people with PIMD (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007; Petry et al., 2005).

Despite the importance of an informal network for people with PIMD, little information is available. First of all, it remains unclear what the characteristics of their social networks are. For one thing, the size and composition are unknown, although they are expected to be small for a lot of the people with PIMD. As mentioned earlier, research into the social networks of people with ID have shown that those networks are indeed small, and mainly consist of family members and peers (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). Due to the severity of their disabilities, it is expected that the structure of the informal networks of people with PIMD is not the identical and probably smaller. If this turns out to be the case, it is worrisome, especially because people with PIMD are dependent on other people

in all aspects of their daily lives and rely on people who know them in order to be understood. Having limited social networks can thus lead to an impoverished lifestyle for people with PIMD. Furthermore, this would confirm the assumption that the informal networks of people with PIMD need more attention. Studies on the informal networks of people with ID have shown that age and type of living arrangement are related to the size of the network (Bigby, 2008; Emerson et al., 2000); this is likely also to be true for people with PIMD. If this is the case, attention should be paid to informal social networks at an early stage, and careful choices in terms of housing (for instance, when moving out of the parental home) should be made.

If a person with PIMD lives at home with his or her parents and siblings, they are usually the ones that make sure this informal network is formed and maintained; moreover, they constitute the network. When persons with PIMD move out of their homes and into a residential facility, this can cause disruption in the maintenance of relationships (Abbott, Bettger, Hampton, & Kohler, 2012). So far, it is not clear how these existing relationships can best be maintained. Even though a move can cause relationships to vanish, it may also create new possibilities. People with PIMD living in residential facilities have contact with other people with disabilities on a daily basis (Lancioni, O'Reilly, & Oliva, 2002). Group members (peers) from the living unit or day-services setting can therefore create opportunities to establish informal relationships (Abbott et al., 2012). Where the relationship with a DSP, a formal network member, is characterized by inequality, this is not the case for a relationship with a group member. Such a relationship is ideally based on choice and equality, where they are not dependent on each other for practical support. Compared to individual activities, people with PIMD spend a large amount of their time in group activities with peers (Vlaskamp, Hiemstra, Wiestra, & Zijlstra, 2007). Such group activities enable people with PIMD and their peers to undertake or experience activities together and, in that way, create long-term caring relationships (Beauchamp & Anderson, 2010). Yet, research has shown that direct support persons (DSPs), even when explicitly requested, rarely stimulate people with PIMD and their peers to interact (Nijs, Penne, Vlaskamp, & Maes, 2015). Even though the people with PIMD in this study showed interest in their peers and showed peer-directed behaviours, DSPs did not recognize such an interest nor did they facilitate these peer interactions (Nijs et al., 2015).

Looking at the benefits that informal social networks provide, it seems only logical that this should be part of the support provided by the formal network. It is known that professionals, when it comes to facilitating social inclusion, are important in terms of mapping social networks, and offering support in maintaining and expanding these (Abbott & McConkey, 2006; Van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014); however, their attitudes for a large part

are the determining factor in the extent to which this happens (Clement & Bigby, 2009). Yet, research shows that, although professionals involved with people with PIMD do support principles like social integration and participation, generally speaking, they do not think these are applicable for people with PIMD (Bigby et al., 2009; Venema, Otten, & Vlaskamp, 2015). It is likely that such attitudes keep professionals from offering support in terms of maintaining and expanding informal social networks for people with PIMD.

The present thesis aims to arrive at a better understanding of the informal social networks of people with PIMD. Not only will the current characteristics of the informal social networks be investigated but also the active steps undertaken by professionals in this regard, as well as their attitudes concerning informal social networks. This information is needed in order to be able to intervene in an appropriate and fitting manner, and, in the long-term, to succeed in creating informal networks that can contribute to the quality of life of people with PIMD.

The main research question of the present study is:

How can the informal social networks of people be maintained and, if necessary, expanded, and what role do professionals play in this matter?

To answer this main question, three sub-questions have been formulated:

- What are the characteristics of the current social networks of people with PIMD?

- What active steps are undertaken by professionals in order to maintain, enhance, or expand these informal social networks?

- What are the attitudes of professionals concerning the topic of informal social networks in persons with PIMD?

1.1. Outline of the thesis

Following on the present introductory chapter, Chapter 2 reports on the structure of informal social networks of 205 people with PIMD. Data was collected by proxy, meaning that, per person with PIMD, two direct support persons were questioned. The results indicated the size of the informal social network, the composition of the network, and the frequency of the contacts. Finally and from this, the type of informal contact person, who most frequently has contact with the person with PIMD, is ascertained.

Chapter 3 analyses how age, communicative abilities, and current living arrangements are related to the number and frequency of the informal contacts, concluding with a discussion of the role of the professional in this regard.

Chapter 4 explores spontaneous interactions between people with PIMD and member of their group in the course of their daily lives. Observational data was obtained from 14 people with PIMD for three consecutive hours. The results describe the type of interactions seen, and with whom, how often, and in what way DSPs enable the interactions between group members. Interactions with group members and the role of the DSP in this regard will be described in more detail. The results show if and how interactions between group members are made possible or hindered by DSPs.

Chapter 5 reports on the content of the individual support plans (ISPs) of 60 people with PIMD, with respect to their informal contacts. The ISPs were inductively coded and, in the results, these codes are illustrated with quotes. Additionally, the results provide information about the content of the ISPs with respect to their history, current situation, and the future they entail, and conclude with the importance of including informal contacts in the ISPs.

Chapter 6 describes the attitudes and active steps on the part of professionals to enhance the informal networks of people with PIMD. Semi-structured interviews were held with DSPs, professionals from daycare, and psychologists, all working with people with PIMD. After transcription of the interviews, these were inductively coded. An overview of the coding scheme and descriptive statistics is provided, illustrated with quotes from the interviews. This serves to clarify whether professionals do find social networks for people important and, if so, why. Further results show what professionals do in order to maintain, strengthen, or expand the networks of people with PIMD, and what they feel are impeding and facilitating factors in this regard.

This thesis concludes with Chapter 7, which reflects on the main findings of all the studies, and answers the main question and sub-questions addressed in this thesis. In conclusion, the limitations of the research are discussed, and implications for practice and research are presented.

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Chapter 2

The structure of informal social networks of persons with profound intellectual and multiple disabilities.

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Abstract

Background: Persons with less severe disabilities are able to express their needs and show initiatives in social contacts, persons with profound intellectual and multiple disabilities (PIMD), however, depend on others for this. This study analysed the structure of informal networks of persons with PIMD.

Materials and Methods: Data concerning the number, type and frequency of contacts were collected in 205 persons with PIMD.

Results: The mean number of contact persons was 5.1 (range: 0–26, SD: 4.2) per year. 79.4% of the contact persons are family, with an average of 72.3 contacts per year. Parents had significantly more contact compared to the other informal contact persons. In 2.2% of the sample contacts with peers were seen.

Conclusions: The informal networks of persons with PIMD consist mainly of family. The question arises how informal networks can be expanded and which role professionals have in this process.

2.1. Introduction

Having social contacts is an important aspect of the quality of life of persons with intellectual disabilities (Schalock & Verdugo, 2002), not only for persons with intellectual disabilities in general, but also for persons with profound intellectual and multiple disabilities (PIMD) (Petry, Maes, & Vlaskamp, 2005). The social contacts of a person can be with many different people and can vary in terms of number and function; taken all together they form a social network. The characteristics of a social network can be distinguished by the structure and function of these contacts (Buysse, 1997; Lippold & Burns, 2009). Structure encompasses the number of different contact persons, the relation between the contact persons and the other person, the frequency of the contacts and the type of contacts. Function encompasses mainly the purpose of the relation, which can be derived from both informal (unpaid) and formal (paid) sources (Forrester-Jones et al., 2006; Bigby, 2008). Buysse (1997) divides the function of the contacts into social–emotional support and practical–instrumental support. Social–emotional support focuses on emotional adaption by means of listening, discussing and advising. This type of support is based on personal ties, rather than employment (Bigby, 2008). Practical–instrumental support has a more problem-solving nature and includes material and concrete help in the form of goods and services.

Studies about the structure and function of the social networks of persons with intellectual disabilities have shown that in general three contact groups are most common: staff, family members and other persons with an intellectual disability. Thus, the social contacts least reported have been those with informal contact persons without disabilities who are not family (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001). It is striking that in the numerous studies, discussions and practical initiatives about the structure of social contacts, barely any attention is paid to the social contacts of people who are the most severely disabled; persons with PIMD. Persons with PIMD have a profound intellectual disability in combination with a severe or profound motor disability and, in many cases, a sensory disability with visual disabilities as most prominent (Nakken & Vlaskamp, 2007). As a result, persons with PIMD are completely dependent on others in almost all aspects of their daily lives. In addition, difficulties in communication reinforce this high level of dependency (Petry et al., 2005). Persons with PIMD experience limitations in signaling and communicating their emotional responses and needs, such as difficulties in communication concerning when and how support should be given (Petry et al., 2005; Schuengel, Kef, Damen, & Worm, 2010). In addition, persons with PIMD are totally dependent on others in the maintenance of social contacts with relatives, friends, acquaintances, peers or staff. With the intensive care needs of persons with PIMD living in a residential facility, it is obvious that they have formal contact persons in their network whose primary goal usually is to

provide practical–instrumental support. To what extent formal contact persons provide social– emotional support during contact moments is unclear. The type of relation often determines the type of support given. Bigby (2008) for instance writes about 'special occasion family' and 'engaged family. The 'special occasion family members' mainly have contact on special occasions, such as at Christmas or on a birthday, and then provide social–emotional support. 'Engaged family' provide both social–emotional support and practical–instrumental support, such as actively monitoring the well-being of the person with PIMD and the support provided to them, and they have contact on a regular basis. The main difference between formal and informal contact persons is the fact that formal contact persons are paid and have a clear job description. Informal contact persons all have their own motives for providing either social–emotional support or practical– instrumental support to a person with PIMD.

Until now, no data are available about the structure and function of the social networks of persons with PIMD in general. This study focuses on the structure of informal social networks of persons with PIMD. Specifically, it aims at providing detailed information about the number of informal contact persons, the relation between the informal contact person and the person with PIMD, frequency and type of the informal contacts of persons with PIMD. Formal contact persons have been excluded and are considered in a separate analysis about the structure and function of the formal network.

2.2. Method

2.2.1. Participants and setting

Because persons with PIMD experience major limitations in communication, information needs to be gathered by proxy. In order to get the best information possible, the choice was made to use the direct support persons (DSP) as the source of information. In the Netherlands, especially in the case of a non-invasive study like our study, ethical approval is obtained from the facility where the study takes place. The research proposal was presented for approval to the participating organisation that informed parents and legal guardians and asked to give their informed consent. The DSPs were the participants in this research, who served as proxies for the persons with PIMD. Inclusion criterion for the DSPs was that they had known the person with PIMD for at least 6 months. All persons with PIMD were selected according to the main characteristics described by Nakken and Vlaskamp (2007). Hence, every person has both a profound intellectual disability and a severe or profound motor disability, leading to being wheelchair bound or leading to little or no use of their hands or arms. The guidelines for a profound intellectual disability are an intelligence quotient of below 20–25 points or an estimated developmental age of up to 24 months (Nakken & Vlaskamp, 2007). Furthermore, only persons were included who are not living at home with parents or family.

The persons with PIMD were recruited from 13 facilities for persons with an intellectual disability across the Netherlands. All persons with PIMD living in these facilities were included, in total 375 persons. All parents and legal representatives of these 375 persons with PIMD were informed and from 205 (54.7%) written informed consent was obtained. The persons with PIMD had a mean age of 48.0 years (range: 13–79, SD = 15.8), 90 were male and 115 were female. Next to diversity in regions, there is variation in the living scheme; 58 participants were recruited from small group homes and 147 persons with PIMD were living in campus settings (Mansell, 2006). 69.8% (143) had visual problems, 26.4% (54) had auditory problems, 31.7% had behavioural problems and 64.9% (133) had epilepsy.

2.2.2. Data and instruments

Data were collected concerning the structure of the social network and investigated as follows: (i) Number of informal contact persons: the total number of different people a person with PIMD had contact with within the 12 months. (ii) The relation between the informal contact persons and the person with PIMD, for instance 'mother' or 'father', 'other person of the living group' (Robertson et al., 2001; Forrester-Jones et al., 2006; Lippold & Burns, 2009). (iii) Frequency of the informal contact; the estimated amount of contact between the informal contact person and the person with PIMD, regardless of the duration of one particular contact. (iv) Type of contact between the person with PIMD and the informal contact person such as calling, visiting, taking the person away from the facility etc. (Baker, Blacher, & Pfeiffer, 1993). Data were gathered through interviews with the DSPs. The interviews were held face-to face by the same researcher with two DSPs about one specific person with PIMD. A semi-structured questionnaire was designed and used in the interviews with the DSPs (see for details Table 1). All of the questions answered concerned the last 12 months.

The aim of the interview was to keep it short and unambiguous through the use of the questionnaire. A pilot version of the questionnaire was therefore tested on intelligibility, user-friendliness and completeness by professionals who worked in a nursing home for the elderly (n = 10). The education level of these professionals was similar to the education level of the professionals dealing with persons with PIMD. The choice was made to use a different target group to test the questionnaire because in this way the group of persons with PIMD was kept as large as possible. Based on the feedback, the questionnaire was adjusted, questions or the response options were adjusted or changed completely, for example adding the options 'per week' and 'per month' in questioning how often someone visited or called, instead of only 'per year'. The first author conducted all the interviews with the two DSPs per participant and therefore visited all the facilities. Appointments with the DSPs were made in advance over the phone with the DSPs themselves or with their team manager.

The questionnaire was retrospective. As the structure of the social network was not stated in detail within the daily reports, the present authors had to rely on the information provided by the DSP. To increase the reliability, two DSPs were asked to answer the same questions and, in case of disagreement, were asked to discuss their answers and achieve consensus. The questionnaire was repeated for each of the informal contact persons in the social network of a person with PIMD.

Table 1 Categories used in the questionnaire.

Relation between person with PIMD and informal contact person					
O	Father				
O	Mother				
O	Brother				
O	Sister				
O	Other family member				
O	Person with disabilities (not a group member)				
O	Neighbour				
O	Volunteer				
O	Other (not family, not a person with disabilities)				
How often has there been contact, per type of contact?					
	Times	Per week	Per month	Per Year	
Calling	-	O	O	O	
Visiting	-	O	O	O	
Away from facility	-	O	O	O	
Other	-	O	O	O	

2.2.3. Analysis

Descriptive statistics have been used to describe the structure of the social networks. First, the number of social contacts with informal contact persons was calculated for each person and the mean, SD and ranges were calculated. Second, the relation between the informal contact persons and the person with PIMD was displayed in percentages of the different kinds of informal contact persons. Third, the frequency of the contacts was calculated in amount per year. Then, the types of informal contact persons were divided into four groups: (i) parents; (ii) brothers and sisters; (iii) other family members; and (iv) other informal contact persons. For every group, the percentages per frequency category were calculated and displayed. Then the mean frequencies of the contacts, per group, were calculated and an analysis of variance (ANOVA) was used to check whether the mean frequency of contact between the four groups was different. If the P-value was smaller than 0.05 ($P < 0.05$), the differences between the groups

were considered to be statistically significant. In that case, a post hoc test was used to find out which groups differed from each other. Finally, the types of contacts with the informal contact persons were calculated. Per category of type contact, percentages were calculated. After this, percentages of the types of contact were given for each of the subcategories; parents, brothers and sisters, other family members and other informal contact persons. Also, descriptive statistics were used to calculate the amount of contacts per year, per type of contact and per type of informal contact person. ANOVA was used to check whether the averages were equal and whether these differed significantly post hoc tests were used to determine which averages were significant.

2.3. Results

2.3.1. Number of informal contact persons

Of all 205 persons involved, 198 (96.6%) had contact with one or more informal contact persons that year. Seven participants (3.4%) did not have contact with any informal contact persons in the last year. In total, 1051 different informal contact persons were involved with an average of 5.1 different informal contact persons (range: 0–26; SD = 4.2) per person with PIMD over the period of 1 year. Almost three-quarters (72.7%, n = 149) of the participants with PIMD had contact with one to six informal contact persons in the recent year, 23.9% (n = 49) had seven or more informal contact persons as contacts and 3.4% (n = 7) had no informal contact persons at all.

2.3.2. Relation between the informal contact person and the person with PIMD

Out of all 205 persons with PIMD included in this study, 45 (22%) had contact with only one parent, 73 (35.6%) had contact with both parents. One hundred and forty-nine persons with PIMD (70.7%) had contact with a brother and/or a sister varying from one up to eight siblings. One hundred and fifteen persons with PIMD (56.1%) had contact with a family member, with a broad range from just one up to 20 other family members. Finally, 104 persons with PIMD (50.7%) had contact with other informal contact persons, varying from one up to 15 other informal contact persons, such as neighbours, volunteers or friends of family members. Concerning the relation between the informal contact persons and the persons with PIMD, 834 (79.4%) of the informal contact persons were family members. Of all the family members, 'other family members' (such as uncles, aunts, grandparents, nieces or nephews) cover the largest part of the social network (34.3%), followed by siblings (26.9%) and finally parents (18.2%). Only 2.2% of the social network consisted of persons with an intellectual disability. The category 'other' contains, for example, friends without disabilities or friends of other members of the social network. Table 2 provides an overview of the relation between the informal contact persons and the person with PIMD.

Table 2 The relation between the informal contact persons and the person with PIMD: number and percentage per category

Type of informal contact person	n	%
Parents	191	18.2
Father	84	8.0
Mother	107	10.2
Siblings	283	26.9
Brother	124	11.8
Sister	159	15.1
Other family members	360	34.3
Other informal contact persons	217	20.6
Person with disabilities	23	2.2
Volunteer	100	9.5
Other	94	8.9
Total	**1051**	**100**

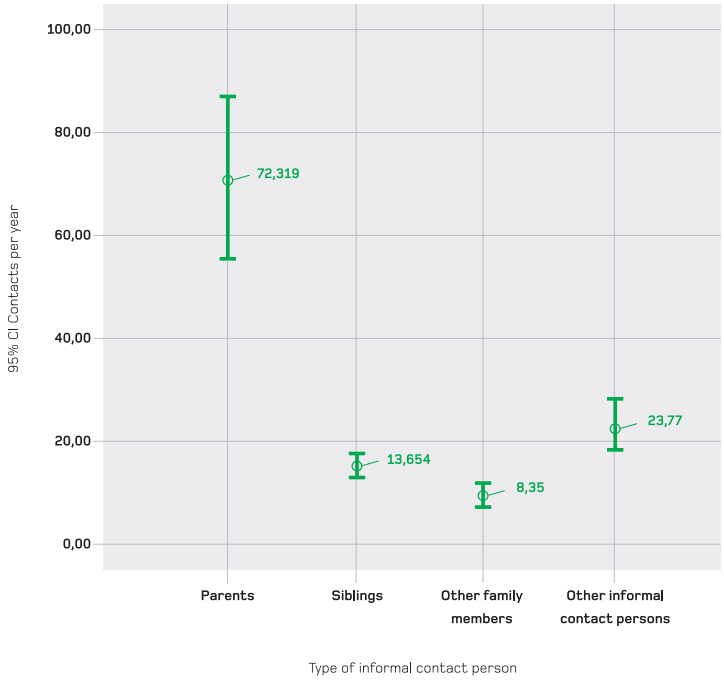

Figure 1: 95% confidence interval of frequency of contacts per year, per category informal contact persons

2.3.3. Frequency of the informal contacts of persons with PIMD

On average, a person with PIMD had contact 24.4 times that year (range: 1–832; SD =54.8) with the nonprofessional within their network. All the informal contact persons taken together (n = 1051), 58.2% had contact less than once a month and over a quarter (29.5%) only had contact once or twice a year. Of all the informal contact persons, 18.6%had contact at least once a week or more.

The mean frequency of contact per category of informal contact persons is shown in Figure 1. Parents had an average of 72.32 contacts, siblings 13.65, other family member 8.35 and other informal contact persons 23.77. The differences in mean frequency between the four groups of informal contact persons are statistically significant ($F = 75.51$, d.f. = 1050, $P < 0.01$).

A Bonferroni post hoc analysis shows that the frequency of contact with parents is significantly higher compared with that of the other groups and that the group 'other informal contact persons' has more contact than the group of 'other family members'.

2.3.4. Type of the informal contacts of persons with PIMD

As for the type of contacts, 84.8% of the informal contact persons visited the person with PIMD in the facility where they lived. Taking a person away from the facility for a stroll, for a stay in the paternal home or for an outing, was performed by 27.3% of the informal contact persons. These two categories, visiting or taking away from the facility, combined, were performed by 96.4% of the informal contact persons. Of all the informal contact persons, 4.6% used phone calls to contact the person with PIMD. Other types of contact, like sending a postcard, were used by 7% of the informal contact persons.

Of all the persons with PIMD (205) 16.6% (34) received one or more phone calls per year, 92.2% (189) were visited once or more, 48.3% (99) were taken away from the facility at least once and 13.7% (28) had one or more other contacts, such as receiving a postcard or an email.

As for the frequency of the contacts, per type of informal contact person, differences have been found within the two most used types of contact: visiting and taking a person away from the facility. An ANOVA shows that there were significant differences between the groups of informal contact persons and the frequency of visiting ($F = 78.24$, d.f. = 1050, $P < 0.01$). A Bonferroni post hoc analysis shows that parents visited significantly more often (mean of 41.9 visits per year) than all the other groups of informal contact persons (siblings; 6.77, other family members; 6.65 and other informal contact persons; 11.40 visits per year). When a person was taken away from the facility, there were significant differences between the categories of

informal contact persons and the frequency of these outings ($F = 27.14$, d.f. = 1050, $P < 0.001$). Parents took their child away significantly more often (mean 18.25 times per year) compared with the other categories (siblings; 4.75, other family members; 0.97, other informal contact persons; 9.25). The group 'other informal contact persons' took a person with PIMD away significantly more often than the category of 'other family members' (9.25 versus 0.97). As for contacts in general, and for visiting and for taking a person away from the facility, parents did this significantly more frequently than all the other categories of informal contact persons.

2.4. Conclusion and discussion

The aim of this study was to explore the structure of the informal social networks of persons with PIMD. We can assume that the data collected over this period of twelve months are representative for all periods of twelve months. This allows us to state that the results show that on average, persons with PIMD have contact with five informal contact persons a year of which 80% is a family member. Only 2.2% of the social network consisted of persons with an intellectual disability. The mean frequency of contact with informal contact persons is low, namely 24.4 per year, where parents have significantly more contact with their child than all other informal contact persons. Even though parents are most frequently involved, only 57.6% of all the persons with PIMD have contact with one or both parents. This means that 42.4% of the persons with PIMD depend on the remaining informal contact persons for social contacts. But this remaining group has significant less frequent contact than parents. Visiting and taking a person away from the facility are the most used forms of contact.

When interpreting the results, the following methodological issues of this study need to be considered. First, because persons with PIMD experience limitations in communication and have severe intellectual disabilities, they are not able to provide information about their informal network. Therefore, gathering information by proxy is the alternative. A disadvantage of this method is that data might be incorrect or incomplete. However, to enhance the reliability of the given information, the interviews were held with two DSPs who had to reach consensus about the number of informal contact persons involved. A more reliable and valid way to get information can be to 'follow' the persons with PIMD in daily life and actually count the number and frequency of (informal) contacts. For practical reasons, this is not feasible, given the group size of 205 persons with PIMD. The information that was collected by the DSP can also be biased as they have no information about the nature and frequency of informal contacts of the person with PIMD outside the facility. For these cases, the number of informal contacts may be higher than reported in this study. Second, concerning the frequency of the contacts, the length of a particular contact is not taken into account. This means that both (very) short and (quite) long contacts are counted as one contact. Third, this study focused on the contacts with informal contact persons. All the

participants live in a facility and therefore also have contact with professionals, but it remains unclear in what way these contacts can also be seen as part of the social contacts and network. Although the results of the current study cannot be generalized to cover the social networks of persons with PIMD in general, the number of persons with PIMD included (205) is very high, especially when the sample size is related to the estimated number of persons with PIMD living in the Netherlands. These figures range between 8.000 and 20.000 (Vlaskamp, 2003; Maes et al., 2008, 2009; Schuurman, 2010; SCP, 2010). That means that in the current study, 1–3% of the whole population was included. It should be taken into account that all the persons involved in this research lived in a residential facility. It is still unclear in what way these results can be applied to, for instance, persons with PIMD still living at home, or with another family member.

Bigby (2008) studied trends in the informal social networks of middle-aged and older people (mean age: 51.5 years) with intellectual disabilities after moving into the community. The size of each person's informal network ranged from 0 to 6 people, with an average of 1.92. This number was based on the number of people that had contact with the person with an intellectual disability and consisted of family and friends. Robertson et al. (2001) found that the median size of a social network, excluding staff members, was two people, with a range of 0–13 different contact persons. The general picture from the current results seems to be much more positive (mean number of five informal contact persons a year) although Robertson et al. (2001) only included people in the network who were considered to be important in someone's individual life. Our research included all contact persons without rating the relationship. Even though Bigby (2008) and Robertson et al. (2001) studied different target groups and used other conditions in order for a person to be considered a network member, their studies provides a general overview of the small network sizes of persons with an intellectual disability. The current research shows similar outcomes which emphasize that besides being small in number, the networks of persons with PIMD also consist mainly of family members.

This is consistent with the findings in the field of persons with intellectual disabilities in general (Robertson et al., 2001; Forrester-Jones et al., 2006; Lippold & Burns, 2009). More specifically, Chou, Chiao and Fu (2011) found that the majority of the primary family carers of adults with PIMD not living in a residential facility were their parents. However, in this research the involvement of other persons with disabilities in the social networks differs between persons with intellectual disabilities in general and persons with PIMD. Persons with an intellectual disability tend to have significantly more friends with intellectual disabilities than friends without such disabilities (Emerson & McVilly, 2004). This can also be expected to be the case when it comes to persons with PIMD. The current study, however, shows that the networks of persons with PIMD barely contain peers; only 2.2% of all the informal contact persons are persons who also

have intellectual disabilities. It is unclear whether these relations do not exist or whether the DSPs interviewed are simply unaware of these contacts or even do not consider such contacts possible. Further studies in which these relationships will be observed in daily practice and compared with social networks diagrams derived from DSPs are recommended.

Concerning the results of the current study, the relation with age is also an interesting topic that needs to be studied. Research shows that as time progresses, in the course of the years, family visits to the facility become less frequent (Blacher, Baker & Feinfield, 1999). Baker et al. (1993) also found that age is related to the degree of involvement of the network; where younger persons with PIMD are concerned the involvement of the network is more intense.

Robertson et al. (2001) and Bigby (2008) found that age was negatively related to the size of social networks of persons with an intellectual disability. Elderly persons with disabilities generally do not have children or a spouse on whom they can depend for support (Bigby, 1997). The same is true for elderly persons with PIMD. On the basis of these findings and the results of the current study, one can assume that the ageing of a person with PIMD probably relates to a smaller number of people in a social network, a less varied network and a lower frequency of contacts. More research on the relationship between age and the structure of the informal contacts of persons with PIMD is needed.

Other research shows that the size and type of the living scheme is strongly related to the size and composition of the social network, and the type of activities undertaken (Emerson & McVilly, 2004; McConkey, 2007). In addition, the previous living scheme seemed to relate to the size of the network; participants who came from their home to the facility had larger social networks than participants who came from somewhere else (Robertson et al., 2001). Further analysis is required to clarify whether the same can be seen in persons with PIMD. This research only included persons with PIMD living in a residential facility and measures were only taken once. It would be interesting to take multiple measures across the lifespan of a person with PIMD concerning social contacts, where the living schemes are taken into account. In particular, comparing the social network of the group of persons with PIMD living with their family to those living in a residential facility, will yield important information. Although the social networks of individuals living within a family might be assumed to be richer, this might not necessarily be the case considering the fact that living in a residential facility means living with peers.

Research also shows that networks for persons with intellectual disabilities mainly consist of staff (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001) and are also related to the type of living scheme. Considering the living scheme of the participants in the current study and their limitations, it can

be assumed that their networks also consist generally of professionals. Further research is required to elaborate on this and also to study the function of these contacts with professionals. Buysse (1997) divides the function of the contacts into social–emotional support and practical– instrumental support. Because of their limitations, persons with PIMD receive a lot of practical– instrumental support, especially from professionals. It remains unclear how much social–emotional support persons with PIMD receive from the professionals. Petry et al. (2005) found that parents and DSPs thought that the well-being of a person with PIMD was affected by the degree to which a DSP felt committed and could express attention, warmth and affection (social– emotional support). At the moment, it is unclear if the contacts with professionals can be seen as social contacts and consequently contribute to a person's wellbeing. A follow-up study should provide more details on the role of professionals in the contact networks of persons with PIMD.

To summarize, follow-up research should focus on the existence of peer relations of persons with PIMD and on the role of professionals in that matter. Furthermore attention should be paid to the relations between the informal social network, age and living scheme. On the other hand, it should also focus on the formal social network of persons with PIMD.

The current study shows that the social networks of persons with PIMD are small. This is worrisome because having a large social network will facilitate social inclusion (Abbott & McConkey, 2006; Bigby et al., 2009; McConkey, 2007). It can also be argued that small networks can be seen as more supportive than large networks (Bigby et al., 2009). Forrester-Jones et al. (2006) state that a wide social network puts less pressure on the professionals and can lead to greater personal freedom and autonomy. The question that arises is in what ways social contacts with people other than parents and professionals can be meaningful for persons with PIMD? In what way, can they benefit from having an extensive social network outside of their direct living environment? Until now, it remains unclear who is responsible for organising the network, professionals or informal contact persons, and how it can be organised that existing contacts are maintained or even expand throughout the years? Considering the fact that persons with PIMD mainly depend on professionals and have contact with them on a daily basis, professionals are probably in a good position to be coordinators of a social network. In order to make this work, a protocol is needed to optimize the social networks of persons with PIMD. The results of the current research are a first step in achieving these goals. More knowledge about the structure and function of social contacts in persons with PIMD and other related factors is needed in order to arrange the best support possible for persons with PIMD and to enhance their quality of life.

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Chapter 3

Informal social networks of people with profound intellectual and multiple disabilities: Relationship with age, communicative abilities and current living arrangements.

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Abstract

Background: People with profound intellectual and multiple disabilities (PIMD) have limited informal social contacts. Research to determine the factors which can positively influence establishing sound informal social contacts is required.

Materials and Methods: Regression analysis for 200 people with PIMD was used to analyse how age, communicative abilities and current living arrangements were related to the number and frequency of their contacts.

Results: Only age was negatively related to both the number and frequency of social contacts. Current living arrangements related only to the frequency of contacts. Communicative abilities related to neither.

Conclusions: Like people with intellectual disabilities, age and living arrangements are related to the informal social networks of people with PIMD. However, for people with PIMD, these networks are already more limited. Therefore, professionals need to be attentive to the maintenance and/or expansion of the social networks of people with PIMD at an early stage.

3.1. Introduction

It is widely acknowledged that having social contacts is an important aspect of the quality of life of people with intellectual disabilities (Schalock & Verdugo, 2002), which is equally true for people with profound intellectual and multiple disabilities (PIMD) (Petry, Maes & Vlaskamp, 2005). All social contacts together form the social network of a person. Social networks have structural and functional characteristics (Buysse, 1997; Lippold & Burns, 2009). The structural characteristics contain the amount of social contact persons, the frequency of the contacts, the type of relation between the network owner and member and the type of contacts. The functional characteristics are the purposes of the contacts, coming from both informal and formal sources (Bigby, 2008; Forrester-Jones et al., 2006; Heaney & Israel, 2008). These two sources can be distinguished by the fact that formal contact persons are paid (professionals) and have a clear job description. Informal contact persons (non-professionals) all have their own motives for providing support to a person with PIMD. Baumeister and Leary (1995) stated that all people generally have the internal drive to obtain and maintain at least a few long-term, positive and special contacts with others. If this is lacking, it can result in severe deprivation with negative effects.

Usually, people without disabilities show initiative in establishing and maintaining their social contacts. This is not the case in people with PIMD. Throughout their lives, they are totally dependent on others in almost every aspect of daily living, including establishing and maintaining informal social contacts (Hostyn & Daelman, 2011; Nakken & Vlaskamp, 2007; Petry et al., 2005). When living at home, parents facilitate these contacts. But when reaching adulthood, most people with PIMD in the Netherlands will move out-of-home to a living arrangement. This will have impact on the social network of people with PIMD. Recent research provided the overall conclusion that informal social networks of people with PIMD, not living with their parents, are small. On average, they have contact with only five informal contact persons per year, of which 80% is a family member (Kamstra, van der Putten, & Vlaskamp, 2015).

Previous research in the general population of people with ID has shown that specific factors such as age and current living arrangements are associated with the size of the social network and the frequency of contacts with non-professional others (Baker, Blacher & Pfeiffer, 1993; Blacher, Baker, & Feinfield, 1999; Robertson et al., 2001; McConkey, 2007; Bigby, 2008). Given the severity of the disabilities and the heterogeneity of people with PIMD, it is doubtful whether these results can be generalized. Moreover, the limited communicative abilities of this group could be related to the size of the informal social network and frequency of the contacts: a person who is able to use words will interact more ably than a person who is only able to use body language.

In order to be able to improve the informal social network of persons with PIMD, more information is needed about factors related to the size of the informal social network and the frequency of the contacts. Therefore, the question addressed in this study is: To what extent is the informal social network size, and the frequency of informal social contacts of people with PIMD related to age, communicative abilities and current living arrangements?

3.2. Method

3.2.1. Participants and setting

A total of 13 living arrangements in the Netherlands participated. After initial approval of the research proposal by the organisation of these facilities, a total of 375 parents or legal representatives of people with PIMD were addressed to obtain informed consent. Written informed consent was received from 54.7% of parents or legal representatives. This yielded 205 people with PIMD about whom information was gathered. All these people had a profound intellectual disability with an estimated developmental age below 2 years, and a severe or profound motor disability. They also had sensory disabilities, especially visual or auditory (Nakken & Vlaskamp, 2007), and difficulties in signaling or communicating their emotional responses or needs (Petry et al., 2005; Schuengel, Kef, Damen, & Worm, 2010). These disabilities and difficulties lead to serious limitations in their daily lives and to limitations in their interactions with others (Hostyn & Daelman, 2011).

Two direct support persons (DSPs) per person with PIMD were asked to participate in an interview: each had to have known the person with PIMD for at least 6 months. A total of 410 DSPs were interviewed: these DSPs knew the people with PIMD an average of 99 months each (range: 6–480, SD = 85.13). All DSPs were formal contact persons and therefore not included in the informal social network.

3.2.2. Measures

Data on the informal network size and the frequency of contacts were collected using an interview with semi closed retrospective questions. Questions were asked about informal social network size over the preceding 12 months and the estimated total number of contacts in a year between the informal contact person and the person with PIMD, regardless of the duration of that contact. In case of disagreement between the DSPs about an answer, they were asked to discuss the answer and achieve consensus.

Age was measured as a continuous variable in years. Communicative abilities were categorized as: (i) body movement, face or eye movement; (ii) vocalisations (i.e. laughing or shouting); and (iii) symbolic forms (i.e. pointing or words) (adapted from Marschik et al., 2012). Each communicative ability category was scored with a yes or no. The current living arrangements were categorized as (i) campus-style settings: houses accommodating about six to eight people, with up to 100 people on the same site and staff available on a 24-h basis; and (ii) small community homes: living in groups of around six people in a house owned by the service provider, with staff available 24 h a day and located within the community (McConkey, 2007).

3.2.3. Analysis

First, descriptive statistics of the variables were calculated. Each participant's sum communicative ability score was calculated, ranging from 1 to 3. The total of all informal contact persons per person with PIMD formed the size of the social network. The 205 participants had an average of 5.1 informal contact persons, (SD = 4.2) of whom five appeared to have 20 or more informal contact persons. No common characteristics were found for these five participants concerning age, communicative abilities and current living scheme. The present authors consider them as a unique group, and the choice was made to leave these participants out of the analyses. Otherwise, results will be biased because of their influence on the analysis. Therefore, all calculations concerning the size of the informal network are performed on the remaining 200 participants.

First a regression analysis was performed with size of social network as dependent variable and age, communicative abilities and current living scheme as explanatory variables. Significant related independent variables ($P < 0.10$) and interactions between variables were included in the model.

The mean of the contacts per person with PIMD was calculated as dependent variable 'frequency of the contacts'. Because the frequency data were positively skewed, the mean frequency of contacts was divided into fitting categories (times per year): 0–5, 6–11, 12–23, 24–51 and >51, based on Baker et al. (1993). Spearman correlation coefficient en Cramers's V were calculated to determine bivariate relations. Significant variables ($P < 0.10$) were included as explanatory variables in an ordinal logistic regression model.

3.3. Results

Table 1 lists the descriptive data for the full sample.

Table 1 Descriptive statistics: percentage or mean (range; SD) N=200

	Mean (range;SD)	Percentage
Age in years	48.07 (13-79; 15.84)	
Gender: male		44.0
Communicative abilities		
1		41.0
2		47.0
3		12.0
Current living arrangements		
Small community homes		28.5
Campus style setting		71.5
Size of network	4.69 (0-16, 3.21)	
Frequency contact (times per year)		
0-5		26.5
6-11		20.5
12-23		21.5
24-51		18.0
>52		13.5

3.3.1. Informal social network size

Age was the only variable significantly associated with the size of the network. Simple linear regression showed that age explained a significant amount of the variance in the size of the social network ($R2 = 0.09$, $F(1.198) = 19.23$, $P < 0.0001$). According to this model, the number of informal contact persons decreases as the person with PIMD ages ($b = 0.06$, $t = 4.39$, $P < 0.0001$). Communicative abilities and living arrangements were not significantly related to the informal social network size. However, including these effects together with their interaction provided non-significant, but interesting interaction effects, as can be seen in Figure 1. The 95% confidence interval for people with three communicative abilities in a campus setting was 2.61–5.74 ($n = 15$), and 4.90–8.99 ($n = 9$) for people living in a small community home. People who had three communicative abilities and were living in a small community home had the most informal contact persons compared with the remaining groups.

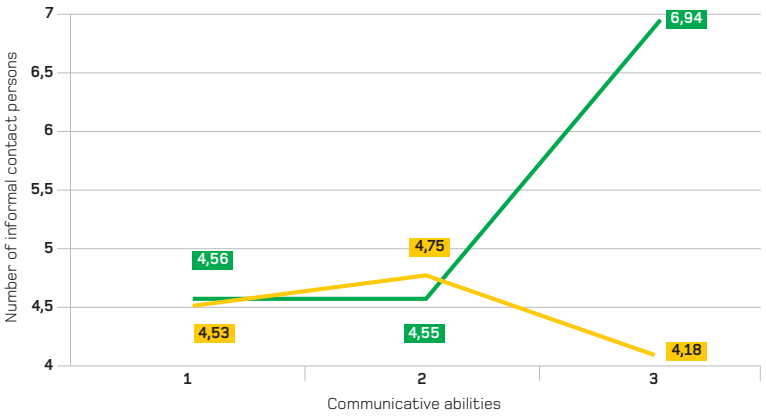

Figure 1 Estimated number of informal contact persons by communicative abilities and living arrangements

3.3.2. Frequency of the contacts

Bivariate analyses showed that age (rs = 0.57, P < 0.0001) and current living arrangements (V = 0.21, P = 0.072) are significantly associated with contact frequency. Including these as explanatory variables in an ordinal regression provided a satisfactory model (chi-square 77.70; P < 0.0001). No significant interaction effects were found. The assumption of parallel lines was not violated (chi-square = 7.28; P = 0.30). The results presented in Table 2 show that age and current living arrangements are negatively related. Being older and living in a campus environment increases the chances of lower frequency of contact.

Table 2 Ordinal logistic regression results concerning frequency of contact with age and living arrangements (N=200)

How often has there been contact, per type of contact?				
	Estimate	SE	Sig	95% CI
Frequency of contact, times per year				
0-5	-5.25	.57	<.0001	-6.36 – -4.13
6-11	-4.07	.53	<.0001	-5.10 – -3.04
12-23	-2.89	.48	<.0001	-3.83 – -1.94
24-51	-1.55	.46	<.001	-2.45 – -0.65
Age in years	-0.07	.01	<.0001	-0.09 – -0.06
Living arrangements				
Campus style setting	-.57	.29	.049	-1.14 – 0

3.4. Conclusion and discussion

The aim of this study was to determine whether the age, communicative abilities and current living arrangements of people with PIMD are related to the size of their social networks and their contact frequency. Social network size appeared to be smaller for older people with PIMD, who also have a lower contact frequency. Living in a campus environment also relates to a lower contact frequency compared with living in a small community home. Communicative abilities are neither significantly related to social network size nor to contact frequency. These results are aligned to the results of other studies of people with intellectual disabilities in general (Baker et al., 1993; Bigby, 2008; Blacher et al., 1999; McConkey, 2007; Robertson et al., 2001).

Our study has some methodological restrictions that need to be taken into account when interpreting its results. Due to the communicative limitations of the people with PIMD, data were collected by proxy. To limit the risks of incorrect or incomplete data, two DSPs were interviewed who had, if they disagreed, to reach consensus about the answers given. Consensus was always reached. Age explained <10% of the variance in the size of the social network. Other factors that can possibly explain the variance in the social networks of people with PIMD are time living in a living arrangement (Blacher, et al., 1999) and strength of the relationships (Bigby et al., 2009). Explanations can also be sought in the characteristics of individual network members; for instance, the physical distance to the living arrangement, age, religion, marital status or socioeconomic status of the network member (Baker et al., 1993). Also environmental factors as: staffing, organisational hygiene and management are known to be related to care practices (Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008) and therefore can possibly contribute to explaining the structure of social networks. Communicative abilities and living arrangements showed a non-significant interaction effect. Calculations were performed without the five participants with a very large network size. When the present authors included these participants in the analyses, the interaction effect for communicative abilities and living arrangements became significant. Given that this result is biased, as the model assumption of homoscedasticity was violated, it is still important to realize that having more communicative abilities and living in a community home seems to lead to a larger network size. Including the five participants in the results concerning the frequency had no effects on the significance. Differences in effect size appeared to be minimal with a maximum of five hundredths. However, participants with large network size are interesting as a group as a whole, where they might provide useful information about the effective factors in social networks.

The trends observed in the social networks of people with PIMD are similar to the people with intellectual disabilities group. However, the social networks of people with PIMD are, in general, already small and restricted to relatives (Kamstra et al., 2015). Networks only seem to shrink as time goes by and no new members appear to be added. This implication supports the conclusions by Bigby (1997) who stated that 'the lack of intergenerational members, shared relationships and situation-specific friendships makes their (older people with intellectual disabilities) informal networks vulnerable to shrinkage'. Furthermore, medical developments have resulted in a longer life expectancy for people with PIMD, which makes it more likely for them to outlive their parents. These parents fear the moment they will no longer be there for their child (Luijkx & Vlaskamp, 2012). People with PIMD are also unable to reach out to others alone, so the environment needs to be proactive in this sense, starting at an early age and continuing throughout the person's life. Therefore, planning for 'replacements' of parents needs to happen actively (Bigby, 1997) in a careful collaboration between informal and formal contact persons. Otherwise, positive changes will not occur and quality of life can be compromised. Early reflection on the composition of the social networks of young people with PIMD is necessary to preventively expand their networks or to fill the gaps that can open over the years. The model for early intervention and family support (Dunst, 2000) can be used as a starting point to do so. Special attention should be paid to creating meaningful relationships within these networks, for instance by understanding what makes interaction meaningful, sharing information with different network members or using social interactions as an activity (Johnson, Douglas, Bigby, & Iacono, 2010; Johnson, Douglas, Bigby, & Iacono, 2012a). People with PIMD need others willing to invest time in them and to develop successful interactions and thereby meaningful relationships. The relationship processes model as provided by Johnson, Douglas, Bigby and Iacono (2012b) may be useful to analyse the current relationships and assist the environment to develop skills in creating and supporting meaningful relationships for persons with PIMD. If this can be achieved, people with PIMD can profit greatly from these social relationships, which will add to their perceived quality of life (Petry et al., 2005; Nakken & Vlaskamp, 2007; Hostyn & Maes, 2009). These meaningful relationships can facilitate social inclusion (Abbott & McConkey, 2006; McConkey, 2007; Bigby et al., 2009; Johnson et al., 2010) and are known to prevent loneliness and negative health effects (Baumeister & Leary, 1995). The role of the professional in 'managing' social networks and the meaningful relationships within them should also be explored further.

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Chapter 4

Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their group members

This chapter is submitted as:
Kamstra, A., van der Putten, A.A.J., Maes, B. & Vlaskamp, C. Exploring spontaneous interactions between people with profound intellectual and multiple disabilities and their group members.

Abstract

Background: Group members form an important source for interactions of people with profound intellectual and multiple disabilities (PIMD). However, given the disabilities of both, the direct support person (DSP) is important, for instance by positioning them in a way that facilitates interaction. This study takes a first step in identifying what is needed to facilitate interactions between group members. Spontaneous interactions of people with PIMD and the possibilities provided by DSPs were observed in a non-controlled situation.

Method: Observational data were obtained from 14 people with PIMD for three consecutive hours, generating a total of 504 observational timeframes.

Results: Of all 213 observed interactions, 5.1% were with group members, 73.4% with DSPs, 14.9% with the observer and 6.5% with others. Generally, the observed positioning of the participants made contacts between group members nearly impossible.

Conclusion: DSPs need to create optimal conditions for interaction between group members through positioning and stimulation.

4.1. Introduction

Social relationships are an important dimension in the concept of quality of life of people with Intellectual Disabilities (ID) (Schalock & Verdugo, 2002). This has also been found to be the case for people with Profound Intellectual and Multiple Disabilities (PIMD) (Petry, Maes, & Vlaskamp, 2005). Social relationships for people with PIMD are believed to prevent for negative health effects and loneliness (Cohen, 2004; Scott & Havercamp, 2014), enable social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle Brown, 2009; Johnson, Douglas, Bigby & Iacono, 2010; McConkey, 2007) and facilitate participation (Petry et al., 2005). Beauchamp and Anderson (2010) stated that long-term supportive social relationships are formed through repeated successful social interactions. These interactions can be defined as activities between two people that are rewarding for both and where the interaction partner is the focus (Beauchamp & Anderson, 2010; Olsson, 2004; Olsson, 2005). Just like everyone else, people with PIMD are in need of positive and meaningful interactions with others (Hostyn & Daelman, 2011; Petry et al., 2005). Where social interactions form a precondition for social relationships, these are of great importance for people with PIMD, however, due to the severity of their disabilities, these interactions are challenging.

People with PIMD are characterized by a combination of profound intellectual and severe or profound motor disabilities (Nakken & Vlaskamp, 2007) and a developmental age of up to 24 months. In addition, most are non-ambulant and the majority also have sensory impairments (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006) which further impede successful interaction with others (Vlaskamp, 2011). Their communicative abilities are generally at a preverbal level, and while some people with PIMD may develop limited spoken or signed expressive language, comprehensive communication will always be minimal. These communicative limitations affect the way people with PIMD interact with others.

An interaction partner of a person with PIMD can be anyone he or she comes across. Studies about interactions of people with PIMD mainly focused on interactions with direct support persons (DSPs) and/or typically developing peers, rather than on interactions with group members (Hostyn & Maes, 2009, Nijs & Maes, 2014). Group members (meaning other service users in the day activities centre or in the group homes) are important in the day to day lives of people with PIMD, as they spend a large amount of time together (Johnson, Douglas, Bigby, & Iacono, 2012). Social interactions with group members would therefore be expected in such situations. Yet research showed that almost no interactions with peers were observed in comparison to interactions with people without disabilities (Logan et al., 1998). In the case of a person with PIMD living in a group home or attending a day care service, interactions can therefore be expected to be with DSPs and group members.

A relationship between a person with PIMD and a DSP is not based on equality where a person with PIMD is dependent of the DSP and not the other way round. Furthermore, the presence of a DSP is based on the work schedule of the DSP; he or she comes and goes. Group members are more equal interaction partners and interaction can occur by choice instead of being inevitable (Gleason, 1989). When the interaction partners are both persons with disabilities, it can be expected that their communicative and interactive strategies will differ from non-disabled interaction partners. Given the lack of a capacity for verbal interaction, positive social interactions between people with PIMD and their group members mainly consist of touching or being physically close to each other (Johnson et al., 2012). Clearly, in such a situation, the limitations of both the person with PIMD and the interaction partner should be taken into account, as they will both have a significant influence.

Beside the person with PIMD and his or her interaction partner, Hostyn and Maes (2009) identified the context as a third component in the interaction. They describe the context as the setting and the circumstances. The setting is not directly related to the individual, but rather the surrounding or the environment a person is in, such as the living environment or the day services setting. The circumstances include the factors directly related to the person with PIMD or the interaction partner, for example, the physical location of the person with PIMD (Hostyn & Maes, 2009) or the physical closeness between the person with PIMD and the interaction partner (Gleason, 1989). Due to their motor limitations, most people with PIMD are unable to move independently, and they are therefore dependent on other actors in their environment, such as DSPs, to be positioned in such a way that it is possible to make contact (Johnson et al., 2012). In other words: the setting needs to facilitate contact. Antelius (2009) argued that positioning is related to what an individual is allowed or able to do: sitting within reach of somebody enables the individual with PIMD to touch the other person and make contact, whereas sitting alone in a room or being further away from others limits all forms of contact for most of these people. As Arthur-Kelly, Bochner, Center and Mok (2008) point out, the position of people with PIMD in relation to others, or the social proximity, should be part of future research. Nijs, Penne, Vlaskamp and Maes (2015) found that there was a relationship between the positioning of children with PIMD and their peer-related behaviour. The most peer-directed behaviour was observed in children who were given the opportunity to see or to touch a peer. It was also found that despite the request to maximise the opportunity for interaction, DSPs positioned the children in such a way that opportunities for peer interaction were minimal. As the circumstantial factor 'position' can easily be adjusted by DSPs, a logical first step is to observe the position of a person with PIMD in relation to the observation of interactions with group members.

While Nijs et al. (2015) investigated interactions among children with PIMD in a controlled situation, it remains unclear whether spontaneous interactions with group members occur in the daily lives of people with PIMD. Furthermore, if such interactions are observed, we do not have a clear idea about the kind of interaction that may occur and what other interactions are seen. Finally, it is unclear what is needed in order to create optimal conditions to facilitate interactions between group members.

The questions addressed in this study are: What types of spontaneous interactions of persons with PIMD are observed in a non-controlled situation and what are the possibilities, provided by DSPs, for interactions with group members?

4.2. Method

4.2.1. Participants

In the Netherlands, especially in the case of a non-invasive study like this study, ethical approval is obtained from the local committee of the organisation where the study takes place. The research proposal was presented for approval to the committees of each participating organisation. After the approval of the local committees, a convenience sample of people with PIMD from three organisations with different types of settings (special education centres, day services settings and group homes) was provided by each organisation. The choice was made to include different types of settings and organisations in order to collect data from broad group. Three groups were randomly selected for each type of setting and only individuals with PIMD who met the criteria of Nakken and Vlaskamp (2007) – diagnosed with a developmental age of less than 24 months and having severe or profound motor disabilities – were included. Being non-ambulant was also used as a selection criterion. This yielded a sample of 21 individuals with PIMD.

The legal representatives of these 21 individuals with PIMD were informed about the study and asked to give their written informed consent. This was given by 18 legal representatives: eight permissions concerned individuals in special education centres and five each individuals in day services settings and in group homes. In the pilot, it became clear that it was impossible to observe more than two participants in one observation, therefore, only two participants were selected from each setting. To minimize the burden on the observed groups the choice was made to observe just once per group. This yielded a total sample size of 14 individuals with PIMD. The mean age of the people with PIMD included in our study was 30.6 years (SD = 17.6). Six participants (42.9%) came from a special education centre, four (28.6%) were observed at their day services setting and four (28.6%) were observed in their group home. The groups were heterogeneous

and sizes varied from five to ten, and the number of DSPs per group varied from one to three. On average, there was one DSP for 4.2 group members (range: 2.5–8, SD = 1.7). For more detailed information about the participants see table 1.

Table 1: participant characteristics

Participant	Sex (f=female, m=male)	Chronological age (in years)	Visual	Able to reach	Observed at
A	F	8	No reported problems	Yes	Special Education Centre 1
B	F	6	Partially sighted	Yes	Special Education Centre 1
C	M	4	Partially sighted	Yes	Special Education Centre 2
D	M	18	No reported problems	Yes	Special Education Centre 2
E	F	16	No reported problems	Yes	Special Education Centre 3
F	F	14	No reported problems	No	Special Education Centre 3
G	F	57	No reported problems	Yes	Day-care Adults 1
H	M	47	No reported problems	Yes	Day-care Adults 1
I	M	33	Blind	No	Group Home 2
J	F	30	No reported problems	Yes	Day-care Adults 2
K	F	53	No reported problems	Yes	Day-care Adults 3
L	M	26	Blind	No	Group Home 1
M	M	46	Partially sighted	No	Group Home 3
N	M	41	No reported problems	No	Group Home 3

The group members of the participants (the observed persons with PIMD) had various disabilities: some were classified as PIMD while others had less severe disabilities. There were differences in the way the group members communicated, the severity of the intellectual disability and the mobility. With respect to the group members, for privacy reasons it was only noted whether they were classified as PIMD, or not. This was only noted if a certain group member interacted with the person with PIMD.

4.2.2. Design

A qualitative research design was employed in the current study. The research is exploratory and two researchers conducted participating observations independently. To ensure objective observations, the observations were structured within an observation scheme and the observers tried not to be involved in conversations or activities. The study is small in order to be able to collect as much data as possible. The results can then be seen as a starting point for further research.

4.2.3. Instrument

An observation scheme was designed to observe group member directed behaviour. This was based on a coding scheme for peer-directed behaviour of people with PIMD that was applied in the study by Nijs et al. (2015). The adjusted scheme included coding for the characteristics of the interaction partner, the interactive behaviours of the interaction partners and the add-on of position changes. This adjusted scheme was tested in a pilot study in two group homes where two individuals were observed (not included in our study) by two independent observers. Interrater reliability was calculated, revealing agreements of 0.46 for "Interactive expressions"; 0.74 for "Was there interaction?"; 0.61 for "Who was the interaction partner?"; and 1.00 for "Was there a change in position?" With the exception of "Interactive expressions," the agreement was 0.61 or higher and therefore sufficient or good (Sim & Wright, 2005). While an agreement of 0.46 is reasonable (Sim & Wright, 2005), the following adjustments were made to the observation scheme: the division of "interactive expressions" into expressions by the person with PIMD and expressions by the interaction partner; the additional category of "details"; and the inclusion of the observer as a possible interaction partner. The category "details" contained information for instance observed activities, if participants had a meal or received medication. The inclusion of the observer as an interaction partner was added because the observers noticed that the individuals with PIMD attempted to make contact with them during the pilot, which could not always be ignored. See Table 2 for the coding scheme used in this study.

Table 2: Coding scheme

Timeframe	Was there a change in position for this person? 0. No 1. Yes (see map)	Was there interaction? 0. No 1. Yes 2. Not in room	Who was the interaction partner? 1. Group member with PIMD 2. Direct support person 3. Group member without PIMD 4. Observer 5. Other	Interactive expressions of the interaction partner 1. Vocalisation 2. Gestures 3. Touching 4. Facial expressions 5. Making sounds 6. Looking at the interaction partner 7. Moving 8. Object related	Interactive expressions of the person with PIMD 1. Vocalisation 2. Gestures 3. Touching 4. Facial expressions 5. Making sounds 6. Looking at the interaction partner 7. Moving 8. Object related	Details

As can be seen in Table 2, the interactive expressions were divided into eight subcategories (based on Nijs et al., 2015): 1. Vocalisation: making sounds, singing, laughing out loud, crying, screaming, whining or talking. 2. Gestures: waving, pointing, nodding or shaking one's head. 3. Touching: hugging, giving hand, stroking the other person, hugging, short touching. 4. Facial expressions: smiling, scowling or pursing lips. 5. Making sounds: hitting the table (of the wheelchair), stamping feet, or any other sounds with materials that attract the attention of the interaction partner. 6. Looking at the interaction partner. 7. Movement: moving the body towards the interaction partner, moving the upper body back and forth or bouncing in the wheelchair. 8. Object related: touching objects, taking objects away from the interaction partner, offering own object to interaction partner, looking at the object of the interaction partner. This will not be scored if the interaction partner puts the object in the hands of the person with PIMD, but only if the person then manipulates the object. It was only possible to score for interaction if the person with PIMD was alert, visible to the observer and if one of the interaction partners responded to the interactive expressions of the other. If the person with PIMD or the interaction partner attempted to initiate interaction but the other person did not respond, this was scored as "no interaction." Reciprocity was a precondition for interaction, regardless of who acted as initiator.

In addition to scoring interactions, the position of the person with PIMD was also mapped. The position of the individual and the position of all other people in the room were noted at the start of the overall observation period and drawn on a map. In accordance with Nijs et al. (2015), these maps allowed us to record whether a participant was in a position to touch a group member or not (not able, able with effort, able from a resting position) and whether a participant could look at a group member or not (not able, able with head movement, able without head movement). Subsequent observations were made in timeframes of five minutes. If an individual was repositioned within a timeframe this was noted as a change of position; if a person was repositioned twice within a timeframe, this was noted as a second change of position. A map was drawn up for every situation in which changes in position were noted, where applicable. If an individual had moved – for example, from the living room to somewhere outside – this was scored as "not in the room." This decision was made because in most observation periods two or three individuals with PIMD were observed simultaneously, making it impossible to observe spaces other than the living room. Furthermore, for privacy reasons, no observations were made if an individual was asleep in his or her bedroom, or if someone was being changed or refreshed. These were all scored as "not in the room."

4.2.4. Procedure

The researchers made an appointment with the DSPs of those units that participated in the study. Overall observation periods lasted for three consecutive hours, with the observation form filled in at the end of every five minutes (one timeframe). In five observation periods two persons with PIMD were observed and in four observation periods one person with PIMD was observed, yielding to a total of nine observation periods and a total of 27 observational hours. In the special education centres and the day services setting, these observation periods took place between 11.30 a.m. and 2.30 p.m. The observation periods in the group home occurred between 4.30 p.m. and 7.30 p.m. These times differed because the participants were not in the group home between 10.00 a.m. and 4:00 p.m. Nevertheless, both observation times included the activity of eating (lunch or dinner) in order to create optimal similarity in the observation periods. No names were noted, instead the participants were assigned an alphabetic character.

Upon arrival in the group home, day service setting or special education centre, the observer introduced herself to the DSPs and shortly explained the purpose of her coming: observing one or two specific persons with PIMD. Next, the observer asked the DSP the following questions about the participants: What are the visual abilities of this person? What are the physical abilities of this person? Does this person interact with others? What behaviours are noticeable prior to this interactions? What behaviours are noticeable during the interaction? What do you see or hear if this person likes something? What do you see or hear if this person does not like something? Then, in consultation with the DSP, the observer was seated in the common room. This had to be a place where the observer was able to see the participants at all time. During the observations the observer did not talk. If a resident tried to make contact this was not rejected, but it was also not initiated or stimulated. If necessary, the observer could change position in order to create a better view. Using a stopwatch, the observer made notes about the past events every five minutes. The timeframes were numbered during the observation in order to recollect at what specific time a certain event or interaction occurred. The observer filled in the observation scheme and wrote down details if needed (for instance if there was a music-therapist working on the group). Per interaction sequence, a row was filled out and the interactive expressions that were used within that particular interaction were noted. If there were more interactions within this five minute timeframe, more rows were filled out. For instance, if a participant interacted with a DSP and with a group member in timeframe number 5, two rows were filled, both numbered as timeframe number 5. When the interaction partner was a group member, it was noted if this group member had a PIMD or not. After three hours the observer talked to the DSP again, now explaining the specific purpose of the observation.

4.2.5. Analysis

For each participant, the observation period included 36 timeframes, thus leading to a dataset of 504 observational timeframes. The timeframes were then analysed to determine the percentage of the timeframes in which an individual was actually observed. It was found that in 47 timeframes (9.3%), the individual was not in the room. Excluding these timeframes left a total of 457 timeframes to be included in the subsequent calculations. In ten timeframes (2.2%) out of this total of 457, the individual was moved out of the room, but it was still possible to score for interaction prior to this and, therefore, these timeframes were included.

All of the interactions and interactive behaviours observed are presented using descriptive statistics. Following this, the interactions with group members will be described more in detail and then presented in an overview which reveals the opportunities for peer interaction.

4.3. Results

4.3.1. Interactions

In 188 (41.1%) of the 457 timeframes, interaction was scored as present. As it was possible to interact with more than one person within an observation period, a total of 213 interactions took place with an average of 15.2 interactions per person (range: 3–33, SD = 8.9). Of these 213 interactions, 5.1% (10) were with a group member, 73.4% (157) with a DSP, 14.9% (32) with the observer and 6.5% (14) with others (a physical therapist, a music therapist and a volunteer).

These 213 interactions, seen in 188 timeframes, included a total of 895 interactive expressions in both directions. The people with PIMD as a group exhibited a total of 364 (40.7%) interactive expressions, and the interaction partners a total of 531 (59.3%). Of all the 531 (100%) interactive expressions of the interaction partners, the DSPs expressed 411 (77.4%), the group members showed a total of 16 (3.0%) interactive expressions, the observer 42 (7.9%) and the other people 62 (11.7%) expressions. For a more detailed overview see Table 3. Compared to the people with PIMD, the interaction partners used more vocalisations. Furthermore, touching was used remarkably more often by the interaction partners than by the people with PIMD, more specifically, most often by the DSPs. It is worth noting that people with PIMD used movement as a form of interacting a lot more than the interaction partners. The DSPs showed the most interactive expressions of all interaction partners (77.4%) and vocalising is their most frequently observed interactive expression. The group members also used vocalising most often to interact.

Table 3: Number of interactive expressions of people with PIMD and their interaction partners

			Interaction partners									
	People with PIMD		DSPs		Group members		Observers		Other		Total interac-tion partners	
	n	%	n	%	n	%	n	%	n	%	n	%
Vocalising	55	15.1	136	33.1	6	37.5	0	0.0	14	22.6	156	29.6
Gestures	2	0,5	10	2.4	0	0.0	0	0.0	4	6.5	14	2.8
Touching	11	3.0	85	20.7	3	18.7	0	0.0	8	12.9	96	18.0
Facial expressions	85	23.4	36	8.8	2	12.5	4	9.5	5	8.1	47	8.8
Sounds	8	2.2	4	1.0	1	6.3	1	2.4	3	4.8	9	1.7
Looking at	97	26.6	75	18.2	1	6.3	32	76.2	14	22.6	122	22.8
Movement	75	20.6	27	6.6	2	12.5	4	9.5	8	12.9	41	7.7
Object related	31	8.5	38	9.2	1	6.3	1	2.4	6	9.7	46	8.6
Total	364	100.0	411	100.0	16	100.0	42	100.0	62	100.0	531	100.0

4.3.2. Interactions with group members

Interaction between a person with PIMD and a group member was observed in only ten timeframes. Table 4 provides a detailed overview of these ten interactions. Of the 14 participants in this study, only five exhibited one or more interactions with a group member during the observation.

These interactions took place in all three special education centres and in one group home, none were observed in the day services setting. It should be noted that the participants with PIMD did not use gestures, touch or object-related expressions in their interactions with a peer. The group members also did not use gestures; however, they did use touch (three times) and object-related expressions (one time). The interactions between group members were: with a group member with PIMD (5 times) and with group members without PIMD (5 times). It is remarkable that when both interaction partners had PIMD, the only interactive expressions observed were vocalisations. The context of the observed interactions with group members are described more in detail as case descriptions in table 5.

Table 4: Interactions between group members and contextual factors

Participant	Sex	Age	Setting	Total interactions with group members	Group members	Timeframe	Interaction PIMD	Interaction group member
B	F	6.8	Special education centre 1	1	PIMD	15	Vocalising	Vocalising
D	M	18.5	Special education centre 1	3	Group member without PIMD	1	Looking Movement	Movement Facial expression Touching
					Group member without PIMD	2	Movement	Movemnet Touching
					Group member without PIMD	3	Movement Facial expression	Touching
E	F	16.5	Special education centre 1	2	Group member without PIMD	22	Looking Vocalising Sounds	Vocalising Sounds Object related
					Group member without PIMD	24	Looking	Movement Facial expression
M*	M	41.1	Group home 3	2	PIMD	15	Vocalising	Vocalising
					PIMD	34	Vocalising	Vocalising
N*	M	46.9	Group home 3	2	PIMD	15	Vocalising	Vocalising
					PIMD	34	Vocalising	Vocalising

* Participant M and participant N were interacting with each other

Table 5: Case descriptions: context of interactions with group members

Participant B is a girl of 6 years old and observed in a Special Education Centre, she was partially sighted and able to reach. According to the DSP, participant B was able to make contact with somebody if that person was within reach of 1 meter, she used throat sounds, smiled, reached toward people or pulled people's hair or clothes. If she was unhappy or not willing to do something she used her arms to push things away or turned her head away. The observation started when there was a music therapist at the group. All group members were positioned in a circle. Participant B was positioned between the bed box and the waterbed (both beds were occupied) facing away from both beds, having a playing rack on her wheelchair desk. She sat there since timeframe 5. Two group members were outside with one DSP. Another occupied bed box was approximately three meters away. One more child (her brother, the interaction partner) sat in the room, about two meters away, turned half away from the table. When they turned their heads they were able to see each other. There was one DSP in the room. Before starting the interaction with the group member (her brother), the observer noticed an increase in sounds by participant B, a DSP responded to one of the sounds in timeframe 14 by vocalising. The amount of sounds made by participant B increased. Interaction with brother by both making sounds.
Participant D is a young man of 18 years old and observed in a Special Education Centre. He has no reported problems with seeing or reaching. According to the DSP participant D is able to make contact with others. If he tries to make contact he is smiling and makes cooing sounds. In contact his whole face smiles and he makes laughing sounds. When he really enjoys something his face lights up and he stretches out his whole body. When he does not like something his face looks scared and he cries, his body starts to cramp. There were three interactions with a group member, all right at the beginning of the observation during a group session with a music therapist. The group was set up in a circle and participant D sat in between two group members, almost wheelchair to wheelchair. This was the position when the interactions occurred. All interactions were with one group member without PIMD. The group member always used touching as an interactive expression, with participant D responding with movement. Participant D also looked at his group member, resulting in a facial expression.
Participant E is a girl of 16 years old, observed in a Special Education Centre, with no reported problems with seeing or reaching. According to the DSP she is able to make contact with other people, she does so by making sounds, facial expressions and eye contact. If she likes something she smiles and raises up her body. If she dislikes something she makes unhappy sounds, as crying of moping, she also uses her arms to bang on her wheelchair table or scratches her ears. She had three interactions with a peer. The first one happened two timeframes after she was positioned at the table for lunch. A group member, who was able to walk, pushed her wheelchair, in reaction she looked at this group member. After a while this group member started talking and making sounds. In reaction participant E also made sounds and vocalisations and started banging on her wheelchair table with her hand (indicating that she did not enjoy this). Two timeframes later the same group member looked at her, participant E responded by vocalising. After another timeframe the DSP started interacting with her. After this, no more interactions with group members occurred.
Participant M and participant N are both male and living in the same group home. They were observed at the same time. Participant M is a man of 46 years , who is partially sighted and not able to reach. Participant N is 41 years old, with no reported visuals problems and not able to reach. According to the DSP participant M makes contact through action – reaction, if a person makes a sound, he responds to that. If he likes something, his body will relax and he smiles. If he does not like something, his body cramps and his feet will go up in the air. Participant N makes contact by facial expressions and moaning sounds, if he likes something, he smiles and makes 'happy' sounds. If he does not like something his lip starts to prowl, he moans or looks away. The first interaction occurred when they were sitting at the table, participant M in a wheelchair with table and participant N in a wheelchair without table. They sat opposite each other at the table. Participant M was sitting at the table for over an hour and the last interaction was with a DSP while he was tube fed over 15 minutes ago. Participant N was sitting the same amount of time at the table and interacted almost every timeframe with the DSP or the observer. Both interactions between participant M and N consisted of vocalisations back and forth. After the first interaction, participant M fell asleep. The second interaction occurred in front of the TV where they were positioned next to each other. This was only seen once for the whole period they were sitting in front of the TV and it happened after over an hour after they have been positioned in front of the TV.

4.3.3 Positions and interactions between a person with PIMD and a group member

The mean number of changes in positioning for all the participants was 4.9 times within a time span of three hours, that is, one overall observation period (SD =

2.2, range: 1–9 times). Table 3 provides an overview of the opportunities for peer interaction for each position. For the participants with PIMD, 61.3% of the time it was not possible to touch a group member or look at a group member. In six timeframes (1.3%), it was possible for the person with PIMD to touch a group member with some effort. For the remainder of the time (98.7%), it was not possible to touch a group member and consequently there was no physical engagement. Table 6 shows positioning and interaction with group members in more detail.

Table 6: Opportunities in relation to positioning and interaction with group members

	Group general		**Interaction with group member**		
	n	%	n	%	Type of interaction with group member
Touching not possible & Looking not possible	280	61.3	3	30.0	Vocalising (3)
Touching not possible & Looking possible with head movement	122	26.7	2	20.0	Vocalising (2)
Touching not possible & Looking possible with head movement	49	10.7	2	20.0	Vocalising (1) Sounds (1) Looking (2)
Touching not possible & Looking possible with head movement	4	0.9	3	30.0	Facial expression (1) Looking (1) Movement (3)
Touching with effort & Looking with head movement	2	0.4	0	0.0	-
Total	**457**	**100.0**	**10**	**100.0**	**14**

4.4 Discussion

The questions addressed in this study were: What types of spontaneous interactions of persons with PIMD are observed in a non-controlled situation and what are the possibilities, provided by DSPs, for interactions with group members? Results show that only 5.1% of all the interactions observed were with a group member, 73.4% of the interactions were with DSPs, 14.9% with the observer and 6.5% with other professionals. The persons with PIMD most often used 'looking at', 'facial expressions' and 'movement' in their interactions. DSPs mostly used 'vocalising', 'touching' and 'looking at'. The observers were 'looking at' the person with PIMD most often and the other interaction partners mainly used 'vocalising' and 'looking at'.

Five (35.7%) out of the 14 participants demonstrated interactions with group members, varying from one to three times during a period of three hours. None of the participants with PIMD used gestures, touching or objects as a means to interact with a group member; vocalisations were observed most often in these interactions. Interactions with group members were observed in the special education centres and in one group home. In general, for 61.3% of the observed time, the participants were positioned in such a way that they were not able to touch or look at a group member. In only four timeframes (0.9% of the time) it was possible for a participant to touch a group member – with some effort – or to look at a group member without effort.

In the current study, only 5.1% of all the observed interactions were with group members, while almost 75% of all the interactions observed were with a DSP. The study by Nijs et al. (2015) discussed previously had similar outcomes, namely that the children with PIMD were focused on the DSP for 67.7% of the observed time, and on their peers for only 8.1% of the time. Due to the limitations of people with PIMD, they are dependent on others in all aspects of their daily life. For DSPs it is their job to support people with PIMD and help them to facilitate interactions with group members. Nijs et al. (2015) found that for almost 95% of the time the DSPs were not focused on facilitating such interactions, even though they had been asked to set up an activity that would maximise the chance of the children interacting with each other. This is in accordance with an ethnographic study by Gleason (1989), who pointed out that 'social simply means what the residents do with one another when left to themselves'. Looking at the results of the current study, as well as the study of Nijs et al. (2015), people with PIMD do not even seem to get this chance. They are not positioned in such a way that interaction is possible and most interaction is with the DSPs, leaving less room for interaction with others, such as group members. The combined findings of both studies strengthen the belief that interactions with group members are not believed to be an essential part of the support required by people with PIMD. This further raises questions about the views and beliefs of professionals concerning the importance and feasibility of interactions between group members.

The most observed interactive expressions of the observed persons with PIMD in this study were 1. looking at, 2. facial expressions, 3. movement and 4. vocalising. In interaction with group members the persons with PIMD showed mostly vocalisations as an interactive expression. This is not consistent with Johnson et al., (2012) who state that social communication in individuals with PIMD mainly consists of touching or being physically close to someone else. This deviating result may be ascribed to the observation that in only 1.3% of the timeframes it was possible to touch a group member. For instance sitting in a wheelchair a few metres apart from each other clearly limits the options for interaction with

group members. This may also explain why gestures, touching or object-related interactions were not observed in the interactions with group members in our research. For 61.3% of the time, the participants were not able to touch and not able to look at a group member. This is striking because the participants included in this research were fully dependent on others to put them in a certain position and create a positive environment.

The participants in this study had a mean change of position of five times, including the changes needed for lunch/dinner and for hygienic reasons. This appears to be representative for the care given to people with PIMD generally, with Van der Putten, Bossink, Frans, Houwen, & Vlaskamp (2016) also finding that the number of transfers and relocations were minimal. Nijs et al. (2015) found that despite the fact that DSPs were asked to offer the children an activity that enabled peer interaction, the DSPs did not position children in such a way that interaction was supported. In fact, during the activity, the children were not moved at all. Optimal body positioning is important for the use of technical aids such as a speech generating device (Costigan & Light, 2010), while also noted for improving functional activities (Bergen, Prespering, & Tallman, 1990), for instance, by training the arm function in such a way that the individual is able to use a technical aid that helps communication or increases mobility (Van der Putten, Vlaskamp, Reynders, & Nakken, 2005). Furthermore, it enables people with PIMD from experiencing the world from different points of view and making contact with others. Positioning can therefore be assumed to be an important precondition for enabling interaction between individuals with PIMD and their peers.

It is necessary to discuss some methodological limitations of this study. Firstly, only 14 individuals with PIMD were observed for a continuous period of three hours. In these three hours timeframes of five minutes were used. This yielded information about a lot of timeframes, however, it did not provide information about for instance the sequence of the interactions, the length of an interaction or the content of the interactions. By conducting a small and exploratory study, it was possible to take all interactions that occurred into account in order to better map what is needed in terms of follow up research and directions for recommendations. Secondly, as a first exploratory study of spontaneous social interactions by people with PIMD, several factors that might have influenced the results may not have been adequately taken into account; for example, the DSPs working at the time, their knowledge of the individual with PIMD and their expertise in PIMD in general, or the activities undertaken on a certain day in the group. We attempted to address the latter by requesting that the observations be made on a typical day. Thirdly, with respect to the individuals with PIMD who were observed, we did not include their additional limitations and/

or abilities or their physical wellbeing as factors that could be related to the variables measured. For example, a participant who is blind will never be able to look at a peer, regardless of the position he or she is in. Nevertheless, knowing about such limitations, DSPs should make the effort to enable social interaction that does not rely on sight. Fourthly, because of the limited observed number of interactions between group members, in combination with the design of the study, the results cannot be considered representative for all people with PIMD, nor for every daily living condition. The results can thus only be understood as a starting point for future research.

Considering the limitations listed above, for any repetition of such a study, it would be recommended to observe a participant more than once, in different situations. This way the elements of the model of Hostyn and Maes (2009): the person with PIMD, the interaction partner and the context can be better mapped and related to the amount and types of interactions. The observation should be an ongoing process, without using the timeframes and noting more detailed information about the observed interactions. Using such observation techniques gathers data that allows for sequential analysis. The advantage of sequential analysis is that it shows if there are sequences in behaviour and if there is a relationship with the context. It is possible to collect this data if solely interactions with group members are to be observed.

4.5. Conclusion

Of the ten observed interactions with group members, in three of them (30%) the participants were not able to touch or see a group member, and the interaction observed in such positions only consisted of vocalisations. This can be seen as a sign that people with PIMD do attempt to interact with their group members, even if conditions are far from optimal. For a DSP this means that he or she needs to play an active role in mediating. If optimal conditions for interaction are created by positioning group members in such a way that interaction is possible and if this interaction is further stimulated, we assume that the number of interactions with group members would increase. In a study of the content of support plans for people with PIMD (Kamstra, Van der Putten, & Vlaskamp, 2016) it was shown that goals related to creating or increasing interaction with group members are lacking. Furthermore, while DSPs could describe interactive behaviours, they also stated that interactive behaviour between group members was non-existent. It seems that it is not clear to DSPs what interaction between group members actually entails, which may lead to a lack of interest in interactions between group members or even a belief that interactions between group members are not feasible for people with PIMD (Bigby et al., 2009) or that is not part of their job (Prain, McVilly, & Ramcharan, 2012). The views and beliefs of DSPs may be one possible reason for the small number of interactions between

group members observed in this study, as well as for the limited conditions they created for interaction between group members. Future research should thus focus on the views and beliefs of DSPs and their related social and physical scaffolding behaviour with respect to interactions between group members and their facilitation in practice.

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Chapter 5

Efforts to increase social contact in persons with profound intellectual and multiple disabilities: analysing individual support plans in the Netherlands

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Abstract

Background: Most people with profound intellectual and multiple disabilities (PIMD) have limited social contact and it is unclear what is done to maintain or increase these contacts. Individual support planning (ISP) can be used in the systematic enhancement of social contacts. This study analyses the content of ISPs with respect to the social contacts of people with PIMD.

Method: ISPs for 60 persons with PIMD in the Netherlands were inductively coded and illustrated with quotations.

Results: It turned out that every ISP contained information about social contacts. Of all the quotations extracted, 71.2% were about current conditions, 6.2% were about the future and less than 1% concerned actual goals. The social contacts of people with PIMD are mentioned in their ISPs, but this is rarely translated into goals.

Discussion: The results of the current study suggest that attention should be paid to ensuring that professionals understand the importance of social contacts and their application in practice.

5.1. Introduction

'Social inclusion', 'participation', 'social interaction' and 'social networks' are only a few of the many terms used in the range of research into the social domain of people with disabilities. The social domain contributes to the quality of life of people with disabilities (Buntinx & Schalock, 2010; Schalock & Verdugo, 2002) and according to the UN Convention on the Rights of People with Disabilities (United Nations, 2006), people with disabilities have the right to participate fully and to be included in society and community life. The social domain is also believedto be of great importance for people with profound intellectual and multiple disabilities (PIMD) (Petry, Maes, & Vlaskamp, 2005).

In general, people are looking for affectively positive interactions within the context of longterm, caring relationships (Baumeister & Leary, 1995). People with PIMD are also in need of positive social relationships with others (Hostyn & Daelman, 2011; Petry et al., 2005). Social relationships are important for several reasons: In addition to facilitating social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Johnson, Douglas, Bigby, & Iacono, 2010; McConkey, 2007), social relationships are known to prevent loneliness and negative health effects (Baumeister & Leary, 1995; Cohen, 2004). Furthermore, social relationships enable participation – physical participation by bringing the person with PIMD into society and mental participation by providing the person with PIMD with a sense of belonging. This makes having social relationships an important aspect of the quality of life of people with PIMD (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007; Petry et al., 2005). However, given the severity of their disabilities, having social relationships is not self-evident for people with PIMD, as they are highly dependent on other people. People with PIMD have a profound intellectual disability with a developmental age of under 2 years, combined with a severe or profound motor disability which often means they require a wheelchair to assist with mobility. In addition, sensory disabilities – with visual disabilities as the most prominent kind (Nakken & Vlaskamp, 2007) – are often present. Long-term caring social relationships are formed through repeated successful social interactions (Beauchamp & Anderson, 2010) which can be seen as activities between two people that are rewarding for both parties (Beauchamp & Anderson, 2010; Olsson, 2004; Olsson, 2005). Such activities, in the broadest sense, can be characterized as social contact. However, due to the severity of the needs of people with PIMD, it is difficult to have successful interactions. Communication is mostly pre- or proto-symbolic for these people (Daelman, 2003). This means that most communicative cues are very subtle, for instance through change in muscle tone, facial expressions, body movement or other cues which are personal or context related. As a consequence, they experience limitations in communicating and signaling their emotional responses and needs (Petry et al., 2005; Schuengel, Kef, Damen, & Worm, 2010). In order to establish successful interactions, it is

important that the social contact person knows the person with PIMD and is able to successfully interpret and respond to the communicative signals. This can only be achieved if there is repeated social contact between the person with PIMD and the social contact person. When successful interactions occur, it is possible that a social relationship is formed. Establishing (new) social relationships is already challenging for people with PIMD, but because of the severity of the disabilities maintaining these relationships is as big as a challenge. People with PIMD need other people to provide personal assistance in establishing and maintaining social relationships.

Social contact with others can be seen as the foundation to satisfy their needs in the social domain for people with PIMD. Social contact in this case is every contact between a person with PIMD and another person, varying from enjoying music together to going out for a walk. Despite the importance of having social contacts, recent research has shown that people with PIMD living in a facility on average have contact with only five social (non-professional) contact persons per year (Kamstra, van der Putten, & Vlaskamp, 2015a). The same study also demonstrated that 80% of the social contact persons are family members, predominantly parents. As people with PIMD become older, they have fewer social contact persons and less frequent contact (Kamstra, van der Putten, Post, & Vlaskamp, 2015b). After moving to a care facility, people with PIMD gradually lose contact with their former social contact persons and do not acquire new social contact persons (Kamstra et al., 2015b). In contrast with people without profound disabilities, who are able to maintain and extend their network naturally, people with PIMD cannot maintain or extend their network by themselves. In addition, because of advanced medical care, people with PIMD have a longer life expectancy than previously, which means that they have come to outlive their parents more frequently. When the passing of a parent occurs, a person with PIMD loses one of the most valuable social relationships. It is understandable that parents frequently worry about this moment: 'what will happen to my child when I am no longer around?' (Luijkx & Vlaskamp, 2012). Despite parental concerns, it is not yet clear how the gap that arises with parental loss can be filled.

In the Netherlands, people with PIMD fall under the 'long-term care act'. Within this law, one of the options is to receive 'care and residence', which entails the combination of receiving care and living in a care facility. In the Netherlands today, when reaching adulthood most people with PIMD move to a care facility (usually near their parents' residence) where care is available 24 h per day. As persons with PIMD are not able to speak for themselves, they need others to do this for them, with parents usually acting as their spokespersons (Jansen et al., 2013). Ideally parents or other legal representatives and professionals determine in close collaboration the support needs of the person with PIMD, specify agreements

and goals to determine what, where, when and by whom support will be delivered, they monitor implementation and evaluate the agreements and goals. This is usually referred to as individual support planning (Herps, Buntinx, & Curfs, 2013) and is initiated by the care facilities by means of an individual support plan (ISP). The use of ISPs is required by law in the Netherlands and usually written by direct support persons (DSPs) under supervision of a behavioural scientist. An ISP is a written document which identifies what a person is able to do in his or her daily life and what support he or she needs to do so (Matousova- Done & Gates, 2006), furthermore it contains specific goals and objectives for the person (Herps, Buntinx, Schalock, Breukelen, & Curfs, 2016). It is stated that the person with PIMD has the right to at least two evaluation moments per year. However, it is common that the caretaker and caregiver together make agreements about the frequency. As mentioned previously, contact with social contact persons is one of the factors contributing to quality of life (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007; Petry et al., 2005). By extension, an ISP should contain information about maintaining and expanding social contacts.

According to several authors, the use of an ISP has multiple benefits (Clark & Gates, 2006; Collins, Mowbray, & Bybee, 1999; Giangreco, Denis, Edelman, & Cloninger, 1994; Herps et al., 2016; Poppes, Vlaskamp, de Geeter, & Nakken, 2002, Poppes, van der Putten, & Vlaskamp, 2011; Van Gemert & Vlaskamp, 1997). By identifying the wishes and needs of the person with PIMD and considering how these needs or desires should be fulfilled, professionals take a better and closer look at the person with PIMD which leads to a more adequate interpretation of their support needs. ISPs can be viewed as a way of systematically documenting and planning interventions to meet the desires and needs of persons with PIMD in all aspects of their lives. An ISP also makes the care process easier to follow and manage and can be used as a guiding instrument for professionals. Using an ISP contributes to better collaboration among professionals from different fields in attaining common goals. Finally, while there is always some staff turnover in the life of a person with PIMD's, an ISP is essential to provide information for 'new' professionals and thus provide some continuity for the person with PIMD. Including social contacts in ISPs seems an obvious and relatively easy way to maintain or expand social contacts.

In sum, it is evident that people with PIMD are in need of social contacts; however, these turn out to be limited. It is unclear how social contacts should be maintained or expanded and by whom. Where ISP provides for the determination of support needs, specifying agreements, implementation and evaluation (Herps et al., 2013), it is usually unclear if or how the task of maintaining or expanding social contacts should be included. Therefore, it is important to know what is provided in the ISPs of persons with PIMD with respect to social contacts. We may discover

what happens in the ISP process and if and how support needs are translated into agreements and thereby form a basis for implementation and evaluation. Analysing ISPs is also a potentially effective way to collect best practice and to be able to exchange useful information. The question addressed in this study is: what do ISPs for people with PIMD currently contain with respect to social contacts?

5.2. Method

5.2.1. Participants and setting

In the Netherlands, especially in the case of a non-invasive study like this study, ethical approval is obtained from the local committee of the facility where the study takes place. At the same time, the research proposal was presented for approval to the legal representatives of the people with PIMD. In the Netherlands, when a person is not able to make independent decisions, a cantonal judge can assign a legal representative. In many cases, this concerns the parents of this person. In the Netherlands, a legal representative stands up for the best interests of the person with PIMD and is by law allowed to make decisions on behalf of the person with PIMD.

All the participants lived at residential facilities in the Netherlands, in 13 locations throughout the Netherlands. A total of 376 people were characterized as having PIMD at these facilities. A random sample of 100 persons was recruited. Legal representatives were asked for their informed consent, which ultimately yielded (after information and reminders) 49 permissions, 2 non-permissions and 49 non-responses. The goal was to analyse at least 60 ISPs, so another random sample of 30 persons was drawn. This time, 15 permissions were received. Written informed consent was ultimately provided by 64 parents or legal representatives. Two ISPs appeared to be empty and it turned out that the person with PIMD did not meet the inclusion criteria for two ISPs. Therefore, a total of 60 participants were included meeting the Nakken & Vlaskamp (2007) criteria: an estimated developmental age of below 24 months with a profound or severe motor disability. Care was available 24 h per day for all participants, 18 (30%) were living in small group homes and 42 participants (70%) were living in a campus environment (Mansell, 2006). The mean age of the participants was 47.2 (range: 10–75, SD ¼ 15.5). Thirty-three (55%) participants were female and 27 (45%) were male. Table 1 provides an overview of the participant characteristics. All the characteristics data were drawn from the ISPs: Because some of the terminology used was inconsistent, more generalized terms have been used here to provide a better overall view of the participants.

Table 1: *Participant characteristics (n=60)*

	N (%)
Cause of limitation	
Prenatal	17 (28.3)
Prenatal	13 (21.7)
Postnatal	12 (20.0)
Unknown	18 (30.0)
Visual problems	
Severe to blind	36 (60.0)
Mild to moderate	5 (8.3)
None	15 (25.0)
Unknown	4 (6.7)
Auditory problems	
Severe to deaf	9 (15.0)
Mild to moderate	10 (16.7)
None	30 (50.0)
Unknown	11 (18.3)
Other	
Epilepsy	38 (63.3)

5.2.2. Data collection

The ISPs were collected digitally by the first researcher, who was granted access to the participants' files. These files were only accessible from a secure working environment, using a personal username and password.

All the text concerning social contacts – understood as contacts with people other than professional support staff – was marked in all the ISPs. To calculate the reliability of the text selection process, both researchers individually selected the text on social contacts from five ISPs. The selected texts were discussed and preliminary guidelines were established to distinguish the passages about social contacts from the rest. Both researchers then again selected text from a further five ISPs. To estimate the agreement between the two researchers on the social contact text, Cohen's k was calculated by counting the number of words on which the two researchers agreed and on those they did not. For the five ISPs, k varied from 0.70 up to 1.00, with an overall agreement of 0.79, which is nearly perfect (Landis & Koch, 1977). The preliminary guidelines for selecting the passages on social contacts were substantial, and slight adjustments were made to the final guidelines to improve inter-rater agreement. The final guidelines can be found in Table 2. Only the text on social contacts was coded.

Table 2: Guidelines for selecting text concerning social contacts

- Only full sentences referring to contacts with non-professionals or group members, including everything that was done and what the response to that was.
- Sentences about contacts with professionals should not be included.
- Volunteers are not regarded as professionals, nor are former professionals.
- Professionals should only be included if they acted as an 'instrument': for example, the professional calls the parents to make an appointment to visit them.
- Activities including the opportunity to meet other people are included, for instance going to church or shopping. This enhances activities which can be assumed to include other people, without knowing in advance whether people will be there. This is about opportunities, not whether they are used.
- The conditions for the realisation of contacts are only included if this relationship is explicit in the text (yes: person x is sensitive of experiencing many stimuli, the professional should warn the contact persons if this is likely to happen, or: in order to visit his parents, person x uses a local taxi. No: person x is sensitive of experiencing many stimuli, or: person x uses a local taxi).
- Text concerning social contacts and history is included, as are previous living groups and daycare groups.
- Daycare is regarded as a possibility to meet others and is therefore included. - If the text literally states how a person comes into contact with someone else, this is included.
- Contacts between professionals and non-professionals concerning issues other than social contacts are not included, for instance contact about medical issues.
- Text about the conditions for social contacts or individual opportunities for making contact are included, for instance: he loves to have people around, or to perform activities where others are needed.

5.2.3. Analysis

Atlas.ti version 7.1.8 was used in the coding process. The first researcher coded the sentences about social contacts and categorized these in several categories (codes) using inductive coding. Inductive coding was done by generating codes through directly examining the data (Christensen & Johnson, 2012). During the coding process, the codes were monitored, new codes were added and codes were merged. Related codes were then grouped in subcategories, and related subcategories were grouped in main categories. This process was carried out in careful collaboration between all three authors of this article. The final coding scheme consists of three main categories, 12 subcategories and 45 codes. Table 3 provides a description of all the main categories, subcategories, the codes and their meanings setting them out using descriptive statistics and, if necessary, illustrating them with quotations.

Table 3: Overview of the main categories, subcategories and codes and their meanings

Category/code	Meaning
1. HISTORY	**Social contacts in the past**
1.1. Informal contact persons	About unpaid contact persons who were involved in the past
1.1.a. Family composition	Composition of the family, for instance parents, brothers and sisters
1.1.b. Persons	Specific mentioning of who was involved
1.1.c. Frequency	The frequency a specific informal contact person was involved
1.1.d. Activities	The activities that were undertaken with an informal contact person
1.1.e. Course	Changes in the social network over the years, for instance the passing of a parent
1.2. Facts/environment	Facts about the physical environment of the person with PIMD
1.2.a. Living group	The name(s) of the living group(s) a person lived in the past
1.2.b. Daycare	The name(s) of the group(s) a person received daycare in the past
1.2.c. Visiting site	The description of a place the person with PIMD visited, usually places they stayed at for a night or a weekend while living at home
1.3. Peers	Description of contacts with peers in the past
1.3.a. Persons	Name(s) of the peer(s)
1.3.b. Frequency	Frequency of contact with a specific peer
2. CURRENT SITUATION	**Social contacts in the present**
2.1. Informal contact persons	Unpaid contact persons involved currently
2.1.a. Content of contact	How contact between the contact person and the person with PIMD is shaped, for instance by telephoning or visiting
2.1.b. Persons	Specific mention of the contact persons involved
2.1.c. Frequency	The frequency of the contacts between the contact person and the person with PIMD
2.2. Peers	Contacts with fellow residents, not just group members but also other persons with an intellectual disability
2.2.a. Content of contact	How contact between the peer and the person with PIMD is shaped, for instance by touching or making noises
2.2.b. Frequency of contact	The frequency of the contacts between the peer and the person with PIMD
2.2.c. Environmental influence	The influence of the environment on these contacts or things the environment does to establish contact between peers
2.2.d. No contact, however actions are observed	Statements that there is no contact with peers, along with descriptions of specific actions between peers
2.3. Person with PIMD	Information concerning the person with PIMD
2.3.a. Behaviour in contact	The behaviour a person with PIMD displays when in contact with others
2.3.b. Opportunities	The opportunities a person has for making contact with others
2.3.c. Obstacles	Description of the obstacles a person with PIMD has in establishing social contacts, and/or the limitations in the environment in establishing such contacts because of the person with PIMD's disabilities

Table 3: continued

Category/code	Meaning
2.3.d. Need for social contact	Statements that the person with PIMD needs social contact or finds it important
2.3.e. Need for social contact not there/ unknown	Statements that the person with PIMD has little or no need for social contact or that this is unknown
2.3.f. Dependence	Description of the person with PIMD's dependence, explicitly in relation to social contacts and the role of the professionals in maintaining these contacts
2.3.g. No social contacts	Statements that this person does not have or barely has any social contacts
2.4. Facts/environment	Facts and opportunities within the environment
2.4.a. Living group	Composition of the living group, its name, and the moment the person with PIMD started living in that particular group
2.4.b. Daycare	Composition of the daycare group, its name and the moment the person with PIMD started participating in that group
2.4.c. Requirements	Description of situations which enable necessary contacts or requirements, for instance the use of a taxi or the health of the person with PIMD
2.5. Activities	Activities that provide opportunities for contact with others besides professionals
2.5.a. Activities with opportunities for contact	Activities where it is possible to get in touch with others. These are activities where other people are present, for instance church or a coffeehouse
2.5.b. Activities in daycare	Activities carried out during daycare
2.5.c. Limitation of activities	Description of activities that are not offered (or no longer offered), but which do offer opportunities for contacts
3. FUTURE	**Social contacts in the future**
3.1. Desires	Desires stakeholders have for the specific person with PIMD concerning social contacts or opportunities to have them
3.1.a. Activities/ participation	Desires for more activities or more participation
3.1.b. Volunteer	Desires for a volunteer for a specific person with PIMD
3.1.c. More contact persons	Desires for more contact persons to expand the social network
3.1.d. Higher frequency of contact	Desires for a greater frequency of contact between the person with PIMD and an existing contact person
3.1.e. Contact with peers	Desires for contacts with peers, or more contacts with peers
3.1.f. Maintain the status quo	Desires to maintain the current social contact situation
3.1.g. Mutual interaction	Desires for more mutual interaction between the person with PIMD and an informal contact person or peer
3.2. Opportunities	Opportunities a person with PIMD has for social contact
3.2.a. Role of professional	The role of the professional in creating opportunities

Table 3: continued

Category/code	Meaning
3.2.b. Within current network	Opportunities to satisfy desires using the current network
3.3. Goals	Goals aimed at social contacts
3.3.a. Activities	Goals aimed at undertaking more activities
3.3.b. Higher frequency of contact	Goals aimed at achieving a higher frequency of contact between the person with PIMD and a contact person or a peer
3.3.c. Participation	Goals aimed at more participation
3.3.d. Expanding social contacts	Goals aimed at expanding the person with PIMD's social contacts
3.3.e. More attention	Goals for the person with PIMD to receive more attention
3.3.f. Operationalization of goals	Elaboration of the goals, how to reach them, when, by whom, etc.

5.3. Results

Table 4 provides an overview of the content of the main categories, subcategories and codes. It shows in how many ISPs a certain code is found and the percentage of the total. Furthermore, it shows how many quotations received a certain code, with the percentage of the total number of quotations. A total of 1340 quotations about social contacts were drawn from the 60 ISPs. The mean number of quotations about social contacts per ISP was 22.3 (SD = 11.0, range = 3–49). Only one code was assigned for 922 quotations (68.8% of the total 1340), 217 quotations (16.2%) received two codes, 145 quotations (10.8%) were given three codes, 47 quotations (3.5%) received four codes, 8 quotations (0.6%) were given five codes and 1 quotation (0.1%) received six codes. This results in a total of 2025 assigned codes, a mean of 33.7 codes per ISP (SD = 17.9, range = 4–69). As shown in Table 4, most of the quotations (71.2%) were about the current social contact situation and the fewest (6.2%) were about the future.

Table 4: Overview of the distribution of the main categories, subcategories and codes

Categories and codes	Number of ISPs (%)	Number of quotations (%)
1. HISTORY	**56 (93.3)**	**459 (22.6)**
1.1. Informal contact persons	*48 (80)*	*246 (12.1)*
1.1.a. Family composition	45 (75)	63 (3.1)
1.1.b. Persons	23 (38.3)	54 (2.7)
1.1.c. Frequency	14 (23.3)	14 (0.7)
1.1.d. Activities	10 (16.7)	16 (0.8)
1.1.e. Course	28 (46.7)	99 (4.9)
1.2. Facts/environment	*55 (91.7)*	*197 (9.7)*
1.2.a. Living group	49 (81.7)	101 (5.0)
1.2.b. Daycare	40 (66.7)	89 (4.4)
1.2.c. Visiting site	6 (10)	7 (0.3)
1.3. Peers	*9 (15)*	*16 (0.8)*
1.3.a. Persons	8 (13.3)	14 (0.7)
1.3.b. Frequency	2 (3.3)	2 (0.1)
2. CURRENT SITUATION	**60 (100)**	**1441 (71.2)**
2.1. Informal contact persons	*60 (100)*	*661 (32.6)*
2.1.a. Content of contact	57 (95)	222 (11.0)
2.1.b. Persons	59 (98.3)	306 (15.1)
2.1.c. Frequency	45 (75)	133 (6.6)
2.2. Peers	*45 (75)*	*131 (6.5)*
2.2.a. Content of contact	31 (51.7)	63 (3.1)
2.2.b. Frequency of contact	26 (43.3)	38 (1.9)
2.2.c. Environmental influence	5 (8.3)	5 (0.2)
2.2.d. No contact, however actions are observed	19 (31.7)	25 (1.2)
2.3. Person with PIMD	*54 (90)*	*251 (12.4)*
2.3.a. Behaviour in contact	25 (41.7)	43 (2.1)
2.3.b. Opportunities	28 (46.7)	50 (2.5)
2.3.c. Obstacles	25 (41.7)	49 (2.4)
2.3.d. Need for social contacts	30 (50)	61 (3.0)
2.3.e. Need for social contacts not there/unknown	5 (8.3)	5 (0.2)
2.3.f. Dependence	21 (35)	30 (1.5)
2.3.g. No social contacts	12 (20)	13 (0.6)
2.4. Facts/environment	*54 (90)*	*168 (8.3)*
2.4.a. Living group	46 (76.7)	67 (3.3)
2.4.b. Daycare	42 (70)	89 (4.4)
2.4.c. Requirements	9 (15)	12 (0.6)
2.5. Activities	*53 (88.3)*	*230 (11.4)*
2.5.a. Activities with opportunities for contact	50 (83.3)	172 (8.5)
2.5.b. Activities in daycare	33 (55)	47 (2.3)
2.5.c. Limitation of activities	10 (16.7)	11 (0.5)

Table 4: continued

Categories and codes	Number of ISPs (%)	Number of quotations (%)
3. FUTURE	**41 (68.3)**	**125 (6.2)**
3.1. Desires	*40 (66.7)*	*111 (5.5)*
3.1.a. Activities/participation	21 (35)	34 (1.7)
3.1.b. Volunteer	11 (18.3)	18 (0.9)
3.1.c. More contact persons	4 (6.7)	4 (0.2)
3.1.d. Higher frequency of contact	5 (8.3)	7 (0.3)
3.1.e. Contact with peers	4 (6.7)	5 (0.2)
3.1.f. Maintain the status quo	29 (48.3)	41 (2.0)
3.1.g. Mutual interaction	2 (3.3)	2 (0.1)
3.2. Possibilities	*2 (3.3)*	*2 (0.1)*
3.2.a. Role of professional	1 (1.7)	1 (0.05)
3.2.b. Within current network	1 (1.7)	1 (0.05)
3.3. Goals	*7 (11.7)*	*12 (0.6)*
3.3.a. Activities	3 (5)	4 (0.2)
3.3.b. Higher frequency of contact	1 (1.7)	2 (0.1)
3.3.c. Participation	1 (1.7)	1 (0.05)
3.3.d. Expanding social contacts	2 (3.3)	3 (0.1)
3.3.e. More attention	1 (1.7)	1 (0.05)
3.3.f. Operationalization of goals	1 (1.7)	1 (0.05)
TOTAL	**60 (100)**	**2025 (100)**

* The sum of the percentages does not always equal 100 because of rounding

5.3.1. Main category: History

No information about social contacts in the past could be found in four ISPs (6.7%). Quotes about the changes in the social network over the years were mainly about the decease of parents or other family members or about taking over the role of parents:

Johnny's brother and sister-in-law are taking over this task from his mother and come over every 14 days to walk with Johnny. (codes: 1.1.b., 1.1.e., 2.1.a., 2.1.b., 2.1.c.)

Other examples from the person's changes in the social network over the years were about moving or broken contacts:

She had contacts with her half-brother for a while, but he has not tried to contact her in the last five years. In 2010 he received an invitation for her fiftieth birthday, but he never responded. (codes: 1.1.b., 1.1.e.)

5.3.2. Main category: Current situation

All ISPs (n=60; 100%) described the current social contact situation. Of the 2025 codes assigned, a total of 1441 (71.2%) were about the current situation. All ISPs mentioned something about informal contact persons. The following quote contains information about the content of the contact, who is involved and how often:

His stepfather comes to visit once a month, he takes Peter for a walk and sits with him. (codes: 2.1.a., 2.1.b., 2.1.c.)

Contacts or the lack of contacts with peers (not just group members, but also other persons with an intellectual disability) were described in 75% of the ISPs (45 ISPs). An example of a contact situation between a person with PIMD and her peers, and the role of the professional, is Anne:

She prefers some peers. She likes to sit with other female group members at certain times. When you point this out, she smiles. It is our job to make sure Anne has these contacts. Sometimes, a peer makes contact with Anne by touching her, most of the time Anne likes this and shows that by smiling. (codes: 2.2.a., 2.2.c., 2.3.a.)

The following quotes are about statements that there is no contact with peers, along with descriptions of specific interactions between peers. This code is assigned to a total of 25 quotations (1.2%), within 19 ISPs (31.7%). Of the 25 quotations thus coded, 18 received this code exclusively:

Lana has no friends; she doesn't make contact with other clients. At daycare, a peer often holds her hand. (codes: 2.2.d.)

The remaining seven quotations received two or three codes, for example Tom, where environmental influence is acknowledged, examples of contact are mentioned, but at the same time it is stated that Tom has no contact with peers:

Tom does not really have contact with his peers. It is the professional's job to encourage contact with his peers. He does hear and/or see other people; you can see a reaction in him. He turns his head and eyes towards the person and makes noises. (codes:2.2.c, 2.2.d).

Then there is Ally, for whom the content of the contact with Jack is described. For both, these contact moments seem rewarding at times. But when physical contact occurs and situation may be dangerous, they are separated as soon as

possible. The contact is described as pure physical contact with no mentioning of the social component.

She has physical contact with one peer on a regular basis. Sometimes Ally takes the initiative in this contact. Most contact comes from Jack. These contacts between Ally and Jack are accidental, they do not have a bond and they do not try to find each other personally. He regularly sits with her on her seat, he doesn't then look around to find another place to sit and sometimes he almost sits in her lap. He then puts his arm around her, to stroke her, or he takes her socks off to play with them. If she does not enjoy this she pushes him away, but most of the time she laughs and just accepts it. As soon as the professionals notice this, they are immediately separated and each put on an individual seat. It does happen that Jack pulls on Ally's helmet; this could lead to dangerous situations. (codes: 2.2.a., 2.2.d.)

The influence of the environment on the peer contacts or actions by the environment to establish contact between peers was described in five (8.3%) ISPs, for example:

We use a sling to get him in and out of his bed box. Jamie likes this a lot because he is then at the same eye height as his peers. We let him swing for a while because he also enjoys the enthusiastic reactions of his peers. (code: 2.2.c., 2.3.b.)

A little less than half of the ISPs mention the opportunities the person with PIMD has for social contacts, for example Mandy who is able to use a Big Mack and in that way is able to engage in social contacts:

She uses a 'Big Mack': device on which Mandy's direct support personnel or other contact persons can leave messages about a fun experience Mandy had. Mandy is able to push the button, in that way she is able to 'talk' about the recorded experience. (code:2.3.b.)

However, besides opportunities, obstacles were mentioned in 25 ISPs (41.7%), where the limitations of the person with PIMD were mentioned as an obstacle for social contact:

Because of his severe intellectual disability, he is unable to recognise people. (code: 2.3.c)

Twenty (33.3%) out of the total of 60 ISPs said nothing about opportunities and obstacles confronting the persons with PIMD with respect to social contacts. Exclusively, obstacles were noted in 12 ISPs (20%) and exclusively opportunities were noted in 15 ISPs (25%). A total of 13 ISPs (21.7%) noted both. An example is

Elsa, for who is described what limits her in social contact, but also what she is able to do:

Because of Elsa's physical limitations she has few opportunities to actively make contact with others. She does watch and follows peers and professionals. (code: 2.2.d., 2.3.b., 2.3.c.)

Over a third of the ISPs mentioned dependence on others in making social contact:

Oscar is unable to establish or maintain contact. Visiting family requires professional help. (code: 2.3.c, 2.3.f)

The need for social contacts was expressed for half the persons with PIMD:

If he stayed at home this would cause so much stress that Luke would become agitated or lonely because he missed social contact with others. (code: 2.3.d.)

Twelve ISPs (20%) mentioned that the person had no social contacts. Most of these quotes stated that the person did not have friends or that the person did not have social contacts except for family. Fifty ISPs (83.3%) noted something about activities which provided opportunities for contacts with other people, for instance visiting church, vacations, clubs for people with PIMD, swimming, shopping, going to the theatre or going for a walk.

5.3.3. Main category: Future

A total of 125 code assignments (6.2%) (in 41 files) were about future social contacts; 19 ISPs (31.7%) did not mention future social contacts at all. Forty ISPs (66.7%) expressed desires concerning future social contacts and seven ISPs (11.7%) formulated goals for social contacts. The most common statements about the future (for almost half of the persons with PIMD), were about maintaining the status quo. No goals were formulated for this desire. The second most common desire was for the person with PIMD to be involved in more activities in society. This was mentioned in 21 ISPs (35.0%) and these desires were translated into goals in three of these ISPs (5%). The desire for more contact persons was observed in four ISPs (6.7%), and a goal was formulated about establishing new contacts in two ISPs (3.3%). However, no desires concerning this topic were expressed in the ISPs where goals were formulated about it. Furthermore, only one ISP (0.05%) operationalized a goal:

Goal: within six months we will have found a volunteer from the church for Ellen. (code:3.3.d)

Operationalization: an email will be sent to the person responsible for volunteers and our community will be consulted. A person from the pastoral service will be consulted, perhaps he or she can help us. (code: 3.3.f.)

Opportunities for social contacts were noted in two ISPs:

It also turns out that there is a niece who wants to come by during the week and go with Julie to the restaurant. (code:3.2.b)

In the future Chris would like to have a watching relationship with a peer. The professionals could help try this. (code: 3.1.e., 3.2.a.)

5.4. Discussion

The question addressed in this study was: what do ISPs currently contain about the social contacts of people with PIMD? It turned out that every single ISP had some information related to social contacts. Most of the information about social contacts in the ISPs analysed was about current social contacts, such as who these informal contact persons are, or what contacts or activities with peers were undertaken. Information on past social contacts was far less common. The least information was obtained about future social contacts. For the future, most information concerned the desires DSPs had for the person with PIMD, though less than 1% of the information contained actual goals in this respect.

Before interpreting the results, some study limitations should be noted. After carefully establishing reliable guidelines for extracting quotes on social contacts, only the first author carried out the coding process. This risks information being processed according to a personal frame of reference. Therefore, to prevent biased coding, these codes and the associated statements were frequently discussed with the other authors of this article throughout the coding process. Moreover, ISPs are written plans and do not necessarily reflect the actions actually undertaken by DSPs. There may be a discrepancy between what is written in the ISPs and the real life of the person, and the written plans are possibly seen as a paper exercise (Mansell & Beadle-Brown, 2004). It is possible that more or even less is done to maintain or expand the social contacts of people with PIMD in daily practice. Research into the effectiveness of ISPs is scarce and procedural requirements seem more important than the outcomes of care (Buntinx & Herps, 2013; IGZ, 2007;). Thus, our results can be regarded as a starting point for future research in this subject and provides us with insights into the ISP process for people with PIMD.

In general, the ISP process starts by determining support needs (Herps et al., 2013). When determining support needs, only 21 ISPs (35%) contained information

about dependence on professionals for expanding or maintaining social contacts. Regarding contacts with peers, only five ISPs noted something about the influence of the environment in establishing these contacts. This indicates that the support needs for expanding or maintaining social contacts were clear for fewer than half of the participants. This is not in line with the belief that persons with PIMD need support in maintaining or expanding social contacts. In addition to determining support needs, specifying agreements and goals are part of the ISP process. However, only seven files and 12 quotations (0.6%) mentioned social contact goals, and only one goal was operationalized. This leads us to conclude that implementation is not achieved in any of the ISPs as regards social contacts. In addition, no aspect of evaluation was noted in any of the ISPs. It seems that a fixed method for maintaining or expanding social contacts for people with PIMD is required to help them fully benefit from the advantages of using an ISP.

People with PIMD have limited social contacts, even though these are of great importance for their quality of life (Kamstra et al., 2015a), and these already few contacts only seem to diminish over time (Kamstra et al., 2015b). This makes it even more striking that only seven of the ISPs included goals concerning social contacts and only two ISPs set goals to expand social contacts. Goals are known to provide direction for support and show what is desirable for the person and how this will be achieved (Van der Putten, Vlaskamp, & Poppes, 2009). Goal setting also appears to be a suitable means to promote social inclusion and can clearly be tailored to individual needs and aspirations (McConkey & Collins, 2010). As for aspirations, merely maintaining the status quo was the expressed desire in almost half the ISPs, though there was no mention in the ISPs how this should be achieved. Other, but less common, desires concerning expanding the social network were about acquiring a volunteer (in 11 ISPs), more social contact persons (in four ISPs) or contact with peers (in four ISPs). The nature of these desires could indicate that the current situation is acceptable for a large group of people with PIMD. Nothing was said about the future at all for another group of people with PIMD (19 ISPs). For these people, it would appear that social contacts are not a key priority in future planning. The direction of their current support barely seems to consider expanding social contacts, which validates the result of Kamstra et al. (2015b) that no new members appear to be being added to the social networks of people with PIMD. If barely any goals or even aspirations are formulated, it is likely that this will receive little to no attention in daily practice.

No goals were formulated concerning contacts with peers, and having contact with peers was mentioned as a desire in only four ISPs. This looks like a missed opportunity for expanding social contacts, because all the participants from this study had access to care 24 h per day at a living unit with peers. They share the same space on a daily basis, and thus form an accessible source of social

contacts. The results show that communicative signals between peers are only seldom recognized as such. No contact was observed between the person with PIMD and a peer in 31.7% of the ISPs, but at the same time, peer interactions were described. Apparently, such actions are not viewed as ways of making contact despite the fact that, according to Hostyn and Maes (2009), most of these actions should be interpreted as communicative behaviour. Peer-directed behaviours, such as looking at a peer, touching a peer or the object he or she is holding, body movements towards a peer, vocalising, gestures or using facial expressions are pre- and proto-symbolic communicative behaviours (Nijs, Penne, Vlaskamp, & Maes, 2015).

Today, it is generally accepted that people with PIMD are capable of building and maintaining meaningful relationships and are able to exert influence on their environment within these relationships (Vlaskamp, Poppes, & Zijlstra, 2005). This contradicts some of the results found in the current study, where 41.7% of the ISPs mentioned difficulties and obstacles to establishing social contacts. These difficulties were described alongside a person's abilities in 21.7% of the ISPs. However, 20% of the files only mentioned difficulties or inabilities. Assuming that a person with PIMD is completely unable to make contact with others will influence how the professional interprets communicative signals and responds to them (Vlaskamp et al., 2005). The views and beliefs of staff are of great importance in determining their actions (Bigby et al., 2009). It would appear that the views and beliefs of some of the professionals in the current research also stand in the way of actively working on social contacts. Follow-up research should analyse whether this assumption accords with actual opinions held by professionals. In line with Bigby et al. (2009), the results of the current study suggest that attention must be paid to the understanding in professionals of the importance of social contacts and their application in practice.

For daily practice, it seems important that a more fixed method for maintaining or expanding social contacts for people with PIMD is designed and implemented. Part of this method should, on the one hand, pay attention to the views and beliefs of professionals in this matter. On the other hand, it should provide knowledge about the importance of social contacts and what peer contacts look like. Social contacts need to become an important and permanent topic within the care for people with PIMD in general and thereby within the ISPs.

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Chapter 6

Attitudes of professionals to enhancing the informal personal networks of people with profound intellectual and multiple disabilities.

This chapter is submitted as:

Kamstra, A., Van der Putten, A.A.J., Kiezebrink, A., Maes, B. & Vlaskamp, C. Attitudes of professionals to enhancing the informal personal networks of people with profound intellectual and multiple disabilities.

Abstract

Background: Personal networks are an important aspect of the quality of life of people with profound intellectual and multiple disabilities (PIMD). To support professionals in enhancing the personal networks of people with PIMD, the attitudes of professionals towards these networks need to be explored.

Method: Semi-structured interviews were conducted with 24 professionals. After transcription and coding, a total of 45 codes were created and 808 quotations were extracted.

Results: All the professionals felt personal networks were important for people with PIMD, especially for inclusion. Personal networks were maintained by focusing on the relationship between the personal network and the person with PIMD or the professional. A total of 58.3% of the professionals stated that networks barely expanded. Professionals indicated twice as many impeding factors as facilitating ones.

Discussion: Professionals experience difficulties in working with networks of people with PIMD, mainly due to the limitations of the target group, other priorities and lack of time.

6.1. Introduction

Having a social network has positive effects on mental, social and physical health (Heaney & Israel, 2008) and is therefore of great importance to everyone. A social network generally consists of all the people a person has contact with (Heaney & Israel, 2008). All these people can be characterized by a degree of closeness and be placed within three dimensions (Baard, Uffing, & Dekkers, 1990): the extensive network, the nominal network and the personal network. The extensive network is composed of all accidental and incidental contacts (knowing a person's face but not necessarily their name), the nominal network consists of people a person indirectly knows and meets. The personal network consists of personal relationships: the long-term and caring relationships characterized by repeated successful or enjoyable social interactions, also regarded as contacts which are rewarding for both parties (Beauchamp & Anderson, 2010; Johnson, Douglas, Bigby, & Iacono, 2012; Olsson, 2004; Olsson, 2005). Furthermore, a personal network can be divided into informal (unpaid) personal networks and formal (paid) personal networks (Bigby, 2008; Forrester-Jones et al., 2006; Van Asselt-Goverts, Embregts, & Hendriks, 2013). The degree of closeness of the people within social networks is subject to constant change, related to age, time and environmental factors. People move between the personal network to the nominal network or even to the extensive network. New people are also added to the social networks from society and people move from the extensive network, through the nominal network, into the personal network (Baars et al., 1990).

For people with profound intellectual and multiple disabilities (PIMD), having relationships is an important aspect of quality of life (Hostyn & Maes, 2009; Nakken & Vlaskamp, 2007; Petry, Maes, & Vlaskamp, 2005). Where a personal network consists of personal relationships, a satisfactory personal network by extension contributes to the quality of life of people with PIMD. People with PIMD are characterized by a profound intellectual disability which can be compared to a developmental age of less than 24 months. Furthermore, they have severe or profound motor disabilities (Nakken & Vlaskamp, 2007). Often these disabilities are accompanied by sensory disabilities and health problems which are more prevalent in comparison to typically developing people (De Cock, 2011; Van Timmeren et al., 2016). Because of the severity of their limitations, people with PIMD experience difficulties in communication (Batshaw, Pellegrino, & Roizen, 2007; Evenhuis, Sjoukes, Koot, & Kooijman, 2009; Petry & Maes, 2006). Most people with PIMD communicate at a preverbal level (Hostyn & Maes, 2009; Petry & Maes, 2006), for example through body language and facial expressions (Vlaskamp, Poppes, & Zijlstra., 2005). Not only is it hard for people with PIMD to express their feelings and needs, the person interacting with the person with PIMD needs to know that person to interpret the communicative expressions correctly and respond to them appropriately (Forster & Iacono, 2008; Hostyn

& Maes, 2009; Vlaskamp et al., 2005). The limitations of people with PIMD make it difficult to have successful interactions with others (Vlaskamp, 2011), while interactions are a precondition for establishing informal personal relationships. Informal personal relationships for people with PIMD are important for several reasons: they can facilitate social inclusion (Abbott & McConkey, 2006; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Johnson, Douglas, Bigby, & Iacono, 2010; McConkey, 2007), prevent loneliness and negative health effects (Cohen, 2004; Scott & Havercamp, 2014), enable participation by bringing the person with PIMD into society and provide the person with PIMD with a sense of belonging (Petry et al., 2005).

Having close personal relationships also makes a person vulnerable: the passing or severance of a personal relationship is associated with greater risks of sickness and death (Stroebe, Schut, & Stroebe, 2007). According to Baumeister and Leary (1995), a person is less vulnerable if there is someone who can fill the void left behind. Having multiple informal personal relationships is therefore of great importance. However, people with PIMD have informal personal contacts with an average of only five people in the course of a year. Furthermore, 80% of these contacts are with family, with the parents being the most prominent contact (Kamstra, Van der Putten, & Vlaskamp, 2015a). As people with PIMD get older, it appears that no new informal personal contacts are added; in fact, older people with PIMD have fewer informal personal contacts (Kamstra, Van der Putten, Post, & Vlaskamp, 2015b). The personal networks of people with PIMD are fragile because there are hardly any substitutes for the parents if they, for whatever reason, are no longer available as a personal relationship. This is worrying given the importance of informal personal networks to people with PIMD.

Because of the high levels of support people with PIMD need, it would appear obvious that people with PIMD should have an extended formal network. However, formal networks are sensitive to change and are often not able to provide social support for longer periods (Heaney & Israel, 2008). Furthermore, if an informal network is small, the formal network plays an important role in maintaining or expanding that network (Abbott & McConkey, 2006) and this should therefore be part of the support provided by the formal network, for instance by describing the current network in individual support plans and defining what is desired concerning its development and how this should be achieved. However, this does not seem to be the case: the individual support plans of people with PIMD rarely contain goals topic 'social contacts' in general (Kamstra, van der Putten, & Vlaskamp, 2016). It seems that no systematical actions being undertaken to enhance the personal networks of people with PIMD. However, it is unknown whether this is in fact the case as it is possible that interventions are being carried out but not written down. Furthermore, it is unknown what the impeding

factors are for maintaining or expanding the personal networks of people with PIMD, for instance the attitudes of professionals.

According to Pickens (2005), an attitude consists of three components: a belief or a thought (cognition), a feeling (affection) and behaviour (an action). Beliefs, thoughts and feelings combined result in behaviour. An attitude is described as the effect of modelling others, learning and direct experiences with people and situations. An attitude influences decisions and guides behaviour (Pickens, 2005). Research shows that professionals interacting with people with PIMD agree on the importance of principles such as social integration and participation, but they do not consider them practicable for people with PIMD (Bigby et al., 2009; Venema, Otten, & Vlaskamp, 2015), which therefore influences their actions. It is possible that their attitudes, how they think about the importance of having informal personal networks and what they feel are impeding and facilitating factors in this matter, affect how they support people with PIMD.

So far it remains unclear what should be done in the formal support of these persons to facilitate their personal relationships. To be able to maintain, strengthen and expand the informal personal networks of people with PIMD, it is necessary to understand the attitudes of professionals towards the personal networks of people with PIMD. Such knowledge can help understand what is currently being done and could clarify where potential problems will arise. To be able to support professionals in maintaining, strengthening and expanding the personal networks of people with PIMD, it is important to explore the thoughts, beliefs, feelings and actions of professionals towards the informal personal networks of people with PIMD. Therefore the questions addressed in this study are:

- What, according to professionals, is the importance of having a personal network for people with PIMD?
- What is being done to maintain, strengthen or expand the personal networks of people with PIMD?
- What, according to professionals, are the limiting and facilitating factors concerning the personal networks of people with PIMD?

6.2. Method

6.2.1. Participants and setting

The research was carried out at eight different locations distributed throughout the Netherlands, all of which belonged to a national organisation providing support to people with intellectual disabilities. A total of eight regions were

identified within this organisation, which together housed a total 376 people with PIMD (understood to mean that they had an estimated developmental age of less than 24 months in combination with a profound or severe motor disability (Nakken & Vlaskamp, 2007)). Of these 376 people with PIMD, a total of 205 were included in previous studies (e.g. Kamstra et al., 2015a; Kamstra et al., 2015b). One of these studies (Kamstra et al., 2016) found that the living unit was related to the structure of the social network. Therefore, stratified random sampling was used based on the location. The participants in the current study were the professionals working with these people with PIMD. The aim was to interview the direct support professionals (DSPs) from the living units of 10% of the people with PIMD of who participated in the previous study. This yielded a goal total of 20 DSPs working at the living units of people with PIMD. In addition to the DSPs from the living units, the aim was to interview one DSP from the day services of every location and one healthcare psychologist per location. The goal total for professionals was therefore 36 (20 DSPs from the living unit, eight DSPs from day services and eight healthcare psychologists).This was needed in order to collect information from different points of view. All the professionals had at least one year work experience in the field of people with PIMD and were currently working with at least one person with PIMD. Because saturation point was reached, a total of 24 professionals were included, the average age of all the professionals combined (12 DSPs living unit, five DSPs day services and seven healthcare psychologists) being 38.9 (range: 23–63, SD: 10.6). The group comprised 23 women (95.8%) and one man (4.2%) working as DSPs at a living unit. The average age of the living unit DSPs was 40.2 (range: 23–63, SD: 12.1), 37.4 for the day services DSPs (range:27–45, SD: 7.1) and 37.9 for the healthcare psychologists (range: 24–49, SD: 10.8). The average years' work experience of the professionals combined was 12.3 (range: 1–37, SD: 8.9): specifically, 14.5 for the living unit DSPs (range: 2.5–37, SD: 10.7), 11.7 for the day services DSPs (range: 5.5–17, SD: 4.5) and 8.9 for the healthcare psychologists (range: 1–12, SD: 7.5). No significant differences were found between the groups for age or years of work experience.

6.2.2. Data collection

Semi-structured interviews were conducted using a standardized interview protocol with open questions. The interview outline was based on the interview protocol of Van Asselt-Goverts, Embregts, Hendriks and Frielink (2010), who studied the experiences of support staff with strengthening and expanding the social networks of people with mild disabilities. The participants were asked if they felt personal networks were important for people with PIMD and why, what they did to maintain, strengthen and expand the personal networks of people with PIMD, why this was done, by whom, how, when, how often, if there were differences per individual, and what they thought were the impeding and facilitating factors. These topics were also discussed in the study by Van Asselt-

Goverts et al. (2010). The interviewer ensured that all topics were discussed by raising them in conversation.

6.2.3. Procedure

The healthcare psychologist who specialized in the target group of people with PIMD was the researcher's contact person for each location. The healthcare psychologist decided which living unit DSPs and which day services DSPs should be interviewed, specifically those who were actively working with people with PIMD. Not all the locations were able to gather the desired number of DSPs, meaning that sometimes other locations stepped in to collect as much data as possible. Appointments were made in advance with all participants. The researcher visited all the participants and interviews were conducted face to face. A saturation point was reached after 24 interviews: new interviews did not yield new information. All interviews were voice recorded; these recordings were transcribed and guidelines were set on how to transcribe silences, intonations and difficult to understand speech. The transcribed interview was sent to the participant to be checked and, if necessary, corrected. Six participants responded, this concerned additions or corrections to utterances which were difficult to understand. These transcribed interviews were used in the analysis.

6.2.4. Analysis

Atlas.ti version 7.1.8 was used. The following steps were taken to ensure sufficient reliability in the coding process:

1. Two researchers read five of the 24 transcripts and coded the interviews based on the coding categories in Van Asselt-Goverts, Embregts and Hendriks (2014): 1. interventions to maintain and strengthen social networks, 2. interventions to expand social networks, 3. impeding factors and 4. facilitating factors. The researchers added the category 'importance' for all text where professionals expressed if and why they thought personal networks were important, and added codes based on reasons from the literature: inclusion or a sense of belonging, participation, preventing loneliness and negative health impacts, development (Abbott & McConkey, 2006; Baumeister & Leary, 1995; Bigby et al., 2009; Cohen, 2004; Johnson et al., 2010; McConkey, 2007), advocacy, and more general reasons which could not be placed in any of the previous categories. The coding process used the categories as presented by Baars et al. (1990): the personal, nominal and extensive networks were each taken into account, as well as society. Furthermore, the formal and informal networks were coded separately (Bigby, 2008; Forrester-Jones et al., 2006; Van Asselt-Goverts et al., 2013).

2. Another five transcripts were coded using the categories as described in the first step. During this coding process, inductive coding was performed by one of the two researchers who generated subcategories by directly examining the data (Christensen & Johnson, 2012). These subcategories were discussed by all the authors of this study and merged where possible. This yielded the model presented in Figure 1 and provides a framework for the social networks of people with PIMD as perceived in this study, where the arrows represent relationships between different types of networks.

3. Based on the framework for the social networks of people with PIMD, two researchers coded five transcripts and discussed the codes assigned, then finalized the codes for those transcripts.

4. Next, one researcher used the framework as presented in Figure 1 and coded all the transcripts.

5. The second researcher coded one interview individually to estimate the agreement between the two researchers. Cohen's Kappa was calculated by counting the quotes the researchers agreed upon. Cohen's Kappa was 0.65, which is substantial (Landis & Koch, 1977).

6. Finally, the second researcher checked all the codes assigned by the first researcher and made some slight adjustments and final decisions where the first researcher was unsure.

7. Considering the high number of quotations per category (every professional mentioned items categorized under 'impeding factors – professional'), it turned out that the specific quotations differed. This category was therefore inductively coded separately by one researcher and checked by the other. This lead to a final coding scheme with a total of 45 codes. These codes were categorized into five main categories: the importance of social networks for people with PIMD, interventions to maintain or strengthen the social network, interventions to expand the social network (with the subcategories how and with who), and impeding and facilitating factors.

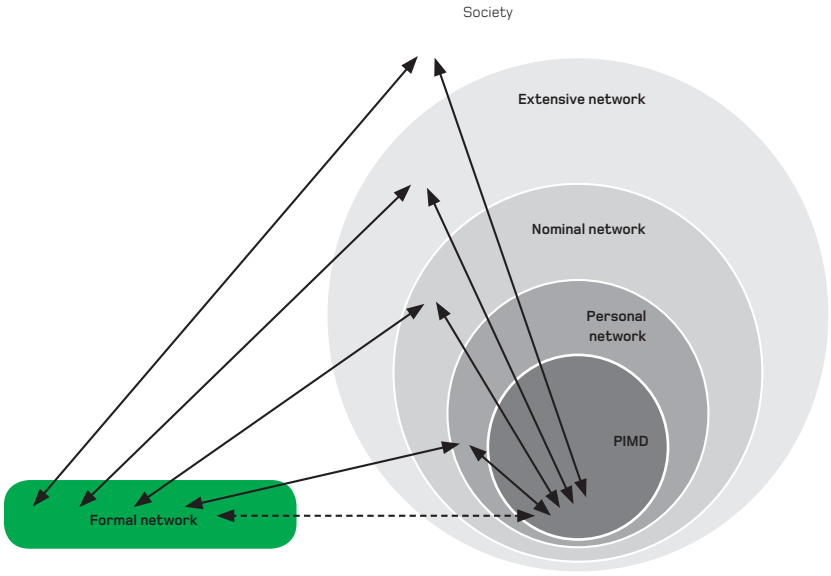

Figure 1: Framework for social networks of people with PIMD

6.3. Results

6.3.1. Number of quotations, codes and coding categories

The 24 interviews lasted an average of 29 minutes and 59 seconds each (range: 18:17-44:43, SD: 7:41). The transcripts of the interviews were divided into 808 quotations concerning the social networks of people with PIMD. A total of 45 codes were created and applied to the quotations. Some of the quotations received more than one code, meaning that a total of 871 codes were assigned. An interview yielded an average of 36.3 codes (range: 19–63, SD: 12.5). Table 1 presents the number of codes and the frequencies for the five main categories.

Table 1: Number of codes and frequencies for the five main categories

Category	Number of subcodes	Number of quotations
1. Importance	6	55
2. Interventions to maintain or strengthen the personal network	5	161
3. Interventions to expand the personal network		
- How	8	76
- With whom	3	40
4. Impeding factors	14	391
5. Facilitating factors	9	148
Total	45	871

6.3.2. Importance

Every professional (n=24; 100%) stated that personal networks were important for persons with PIMD. Six categories of reasons for why personal networks are important could be distinguished: for general development, for inclusion or a sense of belonging, for preventing loneliness and negative health effects, for advocacy, for participation and more general reasons. Table 2 provides an overview of all the codes, examples and frequencies.

The most commonly mentioned reason why personal networks are important for people with PIMD were inclusion or a sense of belonging, followed by participation and general reasons. The following quote is an example of the importance of personal networks for inclusion reasons or a sense of belonging, and a general comment:

So yes, I do think it is very important. Just to feel loved. That somebody loves you. And that somebody thinks you are worth the effort. And that it is possible to feel safe with someone. Yes, it is as important for them as it is for us. (Healthcare psychologist)

Table 2: Overview of codes, examples and frequencies

Codes	Examples	N (%)
1. Importance	**Text about why professionals felt personal networks were important for people with PIMD**	**24 (100)**
Inclusion or a sense of belonging	Being part of something, being yourself, self-esteem	18 (75)
Participation	Activities, widening your horizon	11 (45.8)
General reasons	Because it is important for everyone, it is something you want for everyone	10 (41.7)
Advocacy	Someone who stands up for your rights, someone who knows your history	6 (25)
Preventing loneliness and negative health effects	Network as a stable factor in a person's life, provides energy	5 (20.8)
Development	Important for development, for instance learning new skills	3 (12.5)
2. Maintaining and strengthening	**Actions about maintaining or strengthening the personal networks of people with PIMD, all concerning the existing network**	**23 (95.8)**
None	Statements that maintaining or strengthening the social networks of people with PIMD did not occur	9 (37.5)

Table 2: continued

Codes	Examples	N (%)
Relationship between person with PIMD and personal network, directly	Organising activities, actively inviting people to come and join in (e.g. a barbeque or party), asking them to do activities (swimming, a day out or other daily activities), Skype	19 (79.2)
Relationship between person with PIMD and personal network, indirectly	Attendance at support plan meetings, sending postcards, calls (a professional calls someone from the personal network to talk about the person with PIMD), sending emails, reports or newsletters, taking photos or making videos to show to the personal network	19 (79.2)
Relationship between personal network and formal network	Taking the initiative in calling and trying to be as accessible as possible for the personal network	18 (75)
Personal network	Making the personal network responsible for maintaining or strengthening itself	2 (8.3)
3. Expanding	**Descriptions of efforts to expand the personal network to include people not already in the personal network**	**24 (100)**
How		*23 (95.8)*
None	Statements that expanding the personal networks of people with PIMD did not occur	14 (58.3)
Formal network	Bringing the subject up in the yearly support plan meetings, assigning it as a task to an intern, placing a person with PIMD on a waiting list at a 'volunteer bank' (an organisation which assigns volunteers to clients)	16 (66.7)
Relationship between person with PIMD and society, directly	Going to church, assigning them to clubs, walking around the neighbourhood	5 (20.8)
Relationship between personal network and formal network	Talking about visiting hours, inviting more people to family activities	4 (16.7)
Personal network	Facilitating the exchange of ideas among family members, asking them if they know anyone who is willing to be a volunteer for a person with PIMD	4 (16.7)

Table 2: continued

Codes	Examples	N (%)
Relationship between person with PIMD and society, indirectly	Placing notices (contact advertising) in the supermarket	2 (8.3)
Extensive network	Looking for other service users who are less disabled	2 (8.3)
Relationship between society and formal network	The professional asks around in his or her own network	1 (4.2)
With whom		*20 (83.3)*
Nominal network	Family (aunts and uncles), group members, former DSPs or the families of group members	8 (33.3)
Extensive network	Other service users who are less disabled	5 (20.8)
Society	Volunteers	18 (75)
4. Impeding factors	**Statements on factors which impede working with the personal networks of people with PIMD**	**24 (100)**
Characteristics of person with PIMD	Severity of disability (intellectual and motor), age (older = smaller network), it takes time to get to know someone with PIMD/build a relationship, dependence on others.	23 (95.8)
Personal network	Is already small, acceptance, distance, time.	22 (91.7)
Society	People with PIMD are invisible to society, society does not know this target group or what they need (they often think 'too big'), society is scared	19 (79.2)
Relationship personal network and formal network	Parents and professionals have different views about the person with PIMD, maintaining the relationship with a personal network takes time.	13 (54.2)
History	Hospitalization, placed out of their homes at a very young age, back then 'professionals' knew everything and parents 'nothing', atmosphere and rules in the facilities	7 (29.2)
Relationship between formal network and society	Investing in new network members (from society) takes a lot of time for the professional	3 (12.5)
Relationship between person with PIMD and nominal network	Family members (uncle/aunt) hardly know the person with PIMD	1 (4.2)

Facilitating factors

Table 2: continued	Table 2: continued	Table 2: continued
Relationship between formal network and nominal network	No direct contact between professionals and nominal network	1 (4.2)
Formal network		24 (100)
-Environmental factors	Not enough time/money/staff, no clear policy, remote location of the facility.	23 (95.8)
-No priority	Other things are more important, not a part of the daily care.	14 (58.3)
-Personal opinion	Harder to do your job with network member around, fear, what does an individual need?	9 (37.5)
-Lack of knowledge	Lack of knowledge, no (known) interventions.	7 (29.2)
-Relationship between professionals	Position of daycare services with respect to living unit.	4 (16.7)
5. Facilitating factors	**Statements about factors which facilitate working with the social networks of people with PIMD**	**24 (100)**
Formal network	Volunteer policy, having guidelines, central location of the facility.	18 (75)
Person with PIMD	They evoke caring, young age, making sounds, reactions in contact, small things are perceived as big	17 (70.8)
Personal network	Involved and active personal network, acceptance, views of the personal network about networks	16 (66.7)
Relationship between person with PIMD and personal network	People with PIMD going to their network instead of them coming to the facility, encouraging activities between person with PIMD and the personal network	11 (45.8)
Relationship between personal network and formal network	Investing in relationships, making people feel welcome	9 (37.5)
Relationship between person with PIMD and society directly	Being present in society, explaining the behaviour of person with PIMD to society	7 (29.2)
Relationship between person with PIMD and society indirectly	Looking for people with a common interest, making some sort of profile of the person with PIMD	2 (8.3)
Relationship between person with PIMD and nominal network	Being a part of regular clubs or groups	1 (4.2)
Nominal network	Having fun group members	1 (4.2)

6.3.3. Maintaining and strengthening the social network

The professionals stated in nine interviews (37.5%) that they did not or rarely acted to maintain or strengthen personal networks:

We all think that having social contacts is very important, but we currently rarely pay attention to this. (Living unit DSP)

The professionals stated in 19 interviews (79.2%) that they maintained or strengthened personal networks by focusing directly on the relationship between the person with PIMD and his or her personal network. Maintaining or strengthening the personal network by indirectly focusing on the relationship between the person with PIMD and his or her personal network was also mentioned in 19 interviews (79.2%). The most importance difference with directly focusing on the relationship is that in indirectly focusing, there is no contact between the person with PIMD and his or her personal network, whereas there is in directly focusing. An example of focusing on a direct relation is using Skype:

She used Skype once or twice to contact her mother. She did this on our initiative. (Living unit DSP)

Taking photos or videos to show to the personal network of the person with PIMD are examples of indirectly focusing on the relationship with his or her personal network:

One thing we started at one point was that at every multidisciplinary meeting I attend, I bring photos. At the meeting they [personal network] would receive a folder with photos of their brother or sister from the previous year, especially photos about things the parents, brothers or sisters would not know about the things he or she [the person with PIMD] is able to do, or enjoys. (Daycare services DSP)

Another way professionals try to maintain or strengthen the personal networks of people with PIMD is through the relationship between the professional and the personal network. This was mentioned in 18 interviews (75%) and was done by taking the initiative in calling and trying to be as accessible as possible to the personal network:

We try to invite people in more often if they come to pick someone [the person with PIMD] up. We try to offer them something, to talk to them and make contact. I think that before – of course I cannot be completely sure about how things were before – but, I am under the impression that people [DSPs] were mainly focused on their daily tasks and did not pay much attention to the people with PIMD and their

networks. And they did not take the initiative in this matter, you could say. (Living unit DSP)

Finally, it was stated in two interviews (8.3%) that they tried to maintain or strengthen the personal networks through the personal network:

And we do say that to other parents as well, if there are brothers and sisters who do not come by regularly. We tell these parents that it would be fun if they [the brothers and sisters] would come by more often or [...] well, then the ball is in their court. (Living unit DSP)

6.3.4. Expanding the social network

A total of 14 professionals (58.3%) stated that they did not pay attention to expanding the personal networks of people with PIMD:

No, no. I know that we did discuss it once, like: 'how can we expand the network?' But we never really put those ideas into action. Even though this remains a wish. (Living unit DSP)

Efforts to expand a personal network are usually made by the professionals, most often by putting a person with PIMD on a waiting list at a 'volunteer bank' (a place which assigns volunteers to clients):

Well, when the person [with PIMD] needs to be able to go outside more often, or another activity, then we ask the coordinator of the volunteers. (Living unit DSP)

Another way to expand personal networks is by focusing on the relationships between the person with PIMD and wider society. Consciously bringing a person with PIMD into contact with wider society permits contact with other people:

We try to go out and walk, and if someone walks along with a dog, then we make small talk and try to involve the person with PIMD. But that is just, yes, very minimal. Yes, you try to do it by walking to the town centre or going somewhere. (Living unit DSP)

6.3.5. Impeding factors

The majority of the quotes (44.9%) were about impeding factors. All professionals (n=24; 100%) mentioned factors which impede working with personal networks. Each professional mentioned on average 6.2 impeding factors (range: 2–9, SD: 1.8) All professionals but one (n=23; 95.8%) mentioned the characteristics of the person with PIMD as an impeding factor when working with personal networks:

They are not cute. It is hard, if you do not come over enough you cannot understand them, some talk with their eyes, some with their hands and some only with their posture. They are older, they are not as fun as people with Down syndrome are, who rush to you with a big smile and start chatting and being all enthusiastic. No, they are not always enthusiastic. (Daycare services DSP)

The personal network itself was experienced as a limiting factor in 22 interviews (91.7%):

And P. had a brother who is also her legal representative. And we barely see him here. And I have to call him like, eh, and if he does drop by, I feel like he barely pays any attention to her. (Living unit DSP)

And often family members also age and it [keeping in touch] becomes too hard for them. Obviously we cannot expect them to do it then (Healthcare psychologist)

The society in general is also perceived as a limiting factor:

I think that the target group [people with PIMD] are not in the picture for society and that people within society often do not even know what a PIMD is. (Living unit DSP)

The be unknown is to be unloved. (Living unit DSP)

All 24 professionals (100%) also perceived the formal network as a limiting factor. Environmental factors were mentioned particularly often:

Well, it is very hard. We would really love to see our clients go out. Somewhere in the neighbourhood to go to. There is just no staff to go with them. (Living unit DSP)

But otherwise it is, well look, they [society] do not come inside, so it is pretty isolated here. (Daycare services DSP)

Fourteen professionals (58.3%) mentioned that working with personal networks is not a priority:

I think that other priorities are set. Basic care takes a lot of time, that is being cut. So yes, you have to work very hard. Therefore social contacts have less priority. (Daycare services DSP)

There is little attention paid to expanding social contacts, I think. At least, in the past I did not pay attention to that. It was never really a topic for these people [with PIMD]. (Healthcare psychologist)

The code 'personal opinion' mainly brought together the questions professionals had concerning personal networks for people with PIMD:

What are we doing, what can we do? It is always very subjective. It is my perception when if I say 'I think someone wants five acquaintances in his life'. To really know what someone wants… I find that very difficult. (Healthcare psychologist)

6.3.6. Facilitating factors

Each participant mentioned on average 3.4 facilitating factors for working with personal networks (range: 2–5, SD: 1.2). The formal network itself was the most frequently mentioned as facilitating:

Well, our manager is very engaged, she wants to set things up. Because of her we initiated the 'evening for relatives'. (Living unit DSP)

Openness, something that was lacking in the past. Now we can say, 'you can come over whenever you want to, not a problem'. (Daycare services DSP)

In addition to being perceived as an impeding factor, the person with PIMD was also viewed as a facilitating factor:

Looking after this group, you get a lot of appreciation in return. You can see why you are doing this [going out with a person with PIMD], you can see how happy they are after a walk or a short bike ride. Even that makes them happy, let alone if you take them out all day. I think that those things help us keep doing them. (Living unit DSP)

The personal network itself was also believed to be helpful for working with social networks:

Parents who are still able to think about and help build a network around their son or daughter. Like, there is this one couple who are really focused on creating a network around their son. People to do activities with him: a sister, two volunteers, uncles, aunts who come by regularly. So if his parents are not available, there are plenty others who are. (Living unit DSP)

6.4. Discussion

The first question addressed in this study concerned the opinion of professionals about the importance of having a personal network for people with PIMD. All professionals stated that a personal network was important for people with PIMD, especially with respect to social inclusion or a sense of belonging. The second question concerned the actions professionals undertake to maintain, strengthen or expand the personal networks of people with PIMD. A total of 37.5% stated that they did not consciously maintain or strengthen these personal networks, and another 58.3% indicated that expanding personal networks was not even on their agenda. If maintaining or strengthening personal networks occurred, professionals generally focused on the relationship between the person with PIMD and the personal network, the personal network itself or the relationship between the personal network and the formal network. Interventions for expanding the personal network were mentioned far less often compared to actions related to maintaining or strengthening the network. It was notable that actions are typically expected from the informal network when expanding the networks. For instance, putting a person with PIMD on a waiting list for a volunteer requires at the very least that people become volunteers and thus that someone or some organisation will mediate between the person with PIMD and the volunteer. The responsibility for expanding networks appeared to shift to another party. The third question concerned the limiting and facilitating factors for cooperation with the personal networks of people with PIMD. Professionals mentioned twice as many impeding factors than facilitating factors, which suggests that professionals find working with personal networks for people with PIMD difficult and experience obstacles in cooperation. Not only is the severity and complexity of the disability of the people with PIMD experienced as a limiting factor, professionals also felt that it had no priority in their daily support.

Before interpreting the results, some methodological limitations should be mentioned. First, only the perspective of the professional is taken into account in the present study. Due to the severity of the disabilities of people with PIMD, it is not possible to ask them about their perspectives. To interview members of their personal network would have been an alternative for this lack of self-report. The experiences of members of this personal network could provide interesting and supplementary information on maintaining, strengthening and expanding the social networks of people with PIMD. Second, all the professionals were interviewed individually. To conduct the interviews in groups was considered, because group interviews tend to be more interactive, help participants to explore their views more comprehensively, and encourage the generalization of new ideas (Coenen, Stamm, Stucki, & Cieza, 2012; Van Asselt-Goverts et al., 2014). On the other hand, close attention should be paid to the composition of such groups and the development of trust within a group in order for everyone

to feel comfortable with expressing their own individual thoughts and opinions (Rabiee, 2004). Therefore, we chose to conduct interviews individually. Thirdly, as the current study used qualitative research, there is always a chance of biased coding. We tried to overcome this by establishing clear guidelines developed in careful collaboration between the researchers, checking for sufficient inter-rater reliability, and by one of the researchers performing a final check of the assigned codes. Finally, the participants all worked for the same organisation. This organisation is, however, the largest in the country, covering all regions in the Netherlands and providing support in many different locations, both large and small scale. The results can therefore be regarded as general recommendations for improving the cooperation with the social networks of people with PIMD.

The current study is to our knowledge the first which aimed specifically at strengthening and expanding the social networks of people with PIMD. Van Asselt-Goverts et al. (2014) explored the experiences of professionals concerning strengthening and expanding the social networks of people with an intellectual disability. The results of that study showed that interventions were aimed at the people with intellectual disabilities, for example by psycho-education or by encouraging them to be involved in leisure activities. However, because the study by Van Asselt-Goverts et al. (2014) was of people with less severe intellectual disabilities and no multiple disabilities, those results cannot apply to people with PIMD. This is mainly due to the dependency of people with PIMD on others for maintaining and expanding their networks. This is also reflected by the results in the current study, where actions or interventions are never aimed at the person with PIMD them self. This requires professionals to implement other strategies to maintain, strengthen or expand social networks for people with PIMD.

Van Asselt-Goverts et al. (2014) also found that professionals generally listed a large number of impeding factors. This is in line with the results from the current study, where professionals listed twice as many impeding factors as facilitating factors for maintaining and expanding social networks. Focusing on the obstacles to working with social networks will not motivate actions in this direction as attitudes seem important to determining actions (Bigby et al., 2009). The characteristics of the people with PIMD were mentioned most often as impeding expanding personal networks. Due to the limitations of this target group, professionals state that it takes time to really get to know a person with PIMD and to build a relationship; by extension it takes time to become a part of the personal network. Some professionals noted that explaining the behaviour of the person with PIMD helped in such situations, but that this also takes a lot of time. The current study shows that time is one of the things that professionals feel is lacking. Organisations should help by looking at creative ways to provide professionals with more time. The personal network itself can possibly also be

used to explain or interpret behaviours and thus to facilitate the relationship between the person with PIMD and other network members. If the personal network can explain the meaning of behaviours, less time is needed for another network member to understand the person with PIMD and relationships can then be established more quickly.

Even though all the participants agree on the importance of an informal social network for people with PIMD, they all find it difficult provide this part of the support. Given the actions actually undertaken, maintaining and strengthening an informal network seems to emerge more naturally through daily practice, instead of as a consciously undertaken activity targeted at maintaining or strengthening the informal network. Making people from the networks of people with PIMD feel welcome in their living unit is not necessarily an action which specifically aims at maintaining or strengthening networks, it appears to be more like a bonus. Yet it remains unclear whether the actions undertaken – such as organising activities for personal network members, making calls to the personal network about the person with PIMD or sending postcards – had the desired effect. Do the people from the personal network experience such actions as supporting their relationship with the person with PIMD? This needs to be understood so that professionals can provide support which actually benefits the relationship.

Even where participants were able to explain how they tried to maintain or strengthen an existing personal network, concrete actions appeared to be lacking when it came to expanding the network. Yet expanding the networks is of great importance where the personal networks are small and vulnerable. Results show that if expansion happens, professionals predominantly try to expand with people from society at large. If a network is categorized by its degree of closeness (Baars et al., 1990), people from society in general are the furthest away, with the extensive network a bit closer, followed by the nominal network and the personal network the closest. Therefore, if the goal is to expand the personal network, it seems contradictory to expand it with people from society at large, the most distant network. It would be more obvious to try and get people from the nominal network into the personal network. Furthermore, professionals stated that society does not know the target group of people with PIMD and is therefore not interested in them, and is sometimes even scared of them. Expanding the personal network with people from wider society seems a strategy which is unlikely to succeed. However, when it comes to expanding the extensive network, doing this with people from society seems achievable. Following this line of reasoning, interventions for expanding networks should aim at 'one network closer at a time', meaning that a personal network is ideally expanded with people from the nominal network, the nominal network should be expanded with people from the extended network and the extended network should be expanded with

people from society. This means that the network of people with PIMD needs to be mapped carefully and in close collaboration with people from the personal network, because they know the person with PIMD and his or her networks the best. After mapping the network of the person with PIMD, professionals and the personal network should determine whether they feel that the network is sufficient, and if not, what is needed for the network to become sufficient. Concrete actions should be discussed, taking the abilities and the personality of an individual with PIMD into account, and it should become clear who does what and when. To get this process started, 'the social networks of people with PIMD' needs to be a part of the daily support, with organisations supporting and facilitating this, for instance by training their staff.

The current research confirms that extra attention to the networks of people with PIMD is needed and hoped for. Professionals need practical initiatives to maintain, strengthen and expand the personal networks of people with PIMD consciously. The involvement of personal networks in this matter is of great importance to yield the best possible outcome: a sufficient personal network of people with PIMD with high quality relationships. Follow-up research should thus aim to discover the views, beliefs and wishes concerning the networks of people with PIMD of the people in the personal networks themselves.

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Chapter 7

General discussion

This dissertation presents and analyses data on how to maintain, strengthen, and expand the informal social networks of people with profound intellectual and multiple disabilities (PIMD) in order to be able to intervene in the long term, and to achieve satisfactory informal social networks attuned to the needs and wishes of the individual.

A social network can be considered as "the layout of a group of persons who give to and receive support from one another" (Lunksy, 2006). These people can be divided into two categories: (i) formal network members, people who are part of the network based on payment; and (ii) informal network members, people who are part of the network based on personal reasons (Bigby, 2008; Forrester-Jones et al., 2006; Heaney & Israel, 2008). Within the social network, roughly two different types of support can be received from and provided to its members: practical and emotional support (Buysse, 1997; Heaney & Israel, 2008; Lunsky, 2006). Practical support is about providing goods, services, information, and advice. It is believed that formal network members mostly provide practical support. Emotional support includes expressions of love, empathy, and care, and arises from personal motives rather than employment (Bigby, 2008); it is therefore believed to be provided mainly by informal network members.

Every person is in need of long-term caring relationships that provide emotional support, and this is also true for people with PIMD. By extension, people with PIMD are therefore in need of satisfying informal social networks, including long-term caring relationships. Where multiple research projects have been carried out, which deal with the structure and function of the informal social networks of people with intellectual disabilities, the most vulnerable persons within this group, those with PIMD, rarely seem to be included. The research described in this thesis has been conducted into: (i) the characteristics of the current informal social networks of people with PIMD, (ii) the active steps that are undertaken by professionals in order to maintain, strengthen, or expand these informal social networks, and (iii) the attitudes of professionals vis-à-vis the topic of the informal social networks of persons with PIMD.

7.1. Summary of main findings

The results show that the informal social networks of people with PIMD contain little variety in terms of composition, and are also limited in size. A negative relationship vis-à-vis age is also found: When a person with PIMD becomes older, the size of the informal social network decreases, as does the frequency of contacts (see Chapters 2 and 3). Where the second and third chapters explicitly study informal social contact persons outside the living unit, the fourth chapter observes the interactions with group members and the role that the professional plays in facilitating such contacts. It turns out that interactions

(interactive expressions back and forth) with group members were observed incidentally, especially when compared to the number of interactions with direct support persons. Persons with PIMD barely had any chance to interact with another group member: their physical position relative to other group members made it nearly impossible to interact. In order to explore the active steps that professionals undertake to maintain, strengthen, or expand the current informal social networks, individual support plans (n=60) were analyzed. It turned out that, in general terms, hardly any goals involving social contacts were found at all. In only 8.3% of the plans analyzed, was there any description of the influence of the environment on establishing contacts with other people with disabilities (see Chapter 5). It seems that no steps were undertaken to try to maintain the existing informal social contacts, nor were there any measures taken to expand the informal social networks so as to forestall the expected impoverishment of the networks. In order to understand why there was so little systematic and goal-oriented support for maintaining or improving the social networks of people with PIMD, professionals were interviewed about their attitudes towards the informal social contacts of people with PIMD. The results confirmed that there was hardly any action undertaken to improve the informal social networks of people with PIMD, either within or outside the living unit. Even though professionals believe that social networks are important (see Chapter 6), they also believe that the characteristics of the target group, people with PIMD, are impeding factors. Consequently, the professionals stated that they felt that environmental factors were not supporting them sufficiently to be able to improve informal social networks. This may explain why steps for maintaining, enhancing, and expanding informal social networks are not included in their daily support program. Little effort was made to maintain the informal social networks (see Chapter 6). Visiting was the method most often used by informal contact persons to maintain contact (see Chapter 2). Professionals stated that they worked to maintain these informal social networks by making their members feel welcome (see Chapter 6). It seems that the steps taken by professionals to maintain the informal social networks of people with PIMD are often the result of action taken by the social network members themselves. Therefore, in general it appears that a network member has to take the first step, and then the professionals follow that lead. This way, maintaining informal social networks takes place in a reactive manner, causing professionals to depend on the initiative of the informal social contact persons instead of the professionals themselves being proactive and supportive of informal social contacts through their own initiative. This may also explain why the expansion of informal social networks rarely occurs, if initiatives on the part of the professionals are what are required.

7.2. Methodological reflection

The aim of this research was to collect information on how to maintain, strengthen, and expand the informal social networks of people with PIMD. Although people with PIMD were the target group within this research, the severity of their disabilities prevents them from providing research data themselves. Therefore, professionals were involved in the collection of data throughout the project (see Chapters 2 and 3). This may have resulted in a bias in the results, especially regarding the structure of the informal social network. On the one hand, professionals may have given socially desirable answers so that the informal social networks probably appear to be more extensive than they really are. On the other, professionals may not know all the details about the structure of the informal networks of people with PIMD so that the networks may in fact be larger than stated. Therefore, for more detailed information about the structure of the informal social networks, further studies should focus on monitoring the development of the networks of people with PIMD for a prolonged period of time. A less time consuming alternative would be to involve members of the personal network, and parents in particular, in the data collection. Parents form not only an important and extensive source of knowledge about the person with PIMD, and his or her history (De Geeter, Poppes, & Vlaskamp, 2002; Jansen, Van der Putten, & Vlaskamp, 2013) but also know about the current structure of the informal social network. Nevertheless, our study does provide an important insight into the current situation, in which the size of the informal social network seems to be rather small and strategies for expansion are limited.

A total of 205 people with PIMD participated in these studies: mainly adults from the Netherlands, all living in residential facilities (see Chapters 2 and 3). This sample size is substantial compared to the total number of people with PIMD in the Netherlands. The most recent estimate of the size of the population of people with PIMD is a number of 9639 people with PIMD, of whom 97% were adults (Vugteveen, Van der Putten, & Vlaskamp, 2014). According to Krejcie and Morgan (1970), a representative sample size of a population size of roughly 10,000 would be 370. Of the 375 potential participants for this study, 205 eventually could be included in our research (see Chapters 2 and 3). Furthermore, the average age of the people in the population of the Netherlands (49.23 years, SD: 15.75) and the average age of the people with PIMD in our studies (48.7 years, SD: 15.84) are quite similar. Finally, the people included in our research resided throughout the Netherlands. Therefore, we are confident that the current research provides a good overview of the situation of informal social networks of people with PIMD living in residential facilities in the Netherlands.

This study used multiple techniques for data collection: interviews (see Chapters 2, 3, and 6), observations (see Chapter 4), and analysis of support plans currently in use (see Chapter 5). This provided us with qualitative as well as quantitative data. The quantitative data have become more meaningful in the light of the qualitative data. Furthermore, we were able to compare results from the different studies within this dissertation. This has provided us with a more in-depth understanding of the current situation of informal social networks of people with PIMD.

7.3. Theoretical reflections and future research

Our research has provided information about the structure of the informal social network of people with PIMD. These networks are small in size and not very diverse. It was also found that age was negatively related to the size of the informal social network of people with PIMD, an outcome which is also found in studies on people with intellectual disabilities in general (Bigby, 2008; Dagnan & Ruddick, 1997; Robertson et al., 2001). The main difference between the informal social networks of people with PIMD and those of people with intellectual disabilities in general is that, for people with PIMD, the network is even smaller and even less diverse. Furthermore, the current study showed that, even though professionals unanimously stated that they thought informal social networks were important for people with PIMD, only limited steps were taken to maintain or expand these networks. This is worrisome, since people with PIMD are dependent on others in all aspects of their daily lives (Nakken & Vlaskamp, 2007), including maintaining, strengthening, or expanding their informal social networks. If professionals do not take active steps, the informal social network is left to do so on its own, yet these informal social networks have very few members. This tends to create a vicious circle that needs to be broken in order to achieve satisfactory informal social networks for people with PIMD.

Despite their disabilities, people with PIMD are assumed to be capable of building meaningful relationships. These relationships play an important role for people with PIMD in terms of being able to have control over their own lives (Vlaskamp, Poppes, & Van der Putten, 2015). When other people recognize the communicative signals of a person with PIMD and respond accordingly, the person with PIMD experiences that he or she is being "heard" and in that way is able to influence his or her own life (Vlaskamp, Poppes & Zijlstra, 2005). These communicative interactions will then become successful and perhaps enjoyable, rewarding for both parties, and can form the basis for a social relationship (Beauchamp & Anderson, 2010; Johnson, Douglas, Bigby, & Iacono, 2012; Olsson, 2004, 2005). The hypothesis that people with PIMD are able to establish such relationships is widely acknowledged (Forster & Iacono, 2008; Gleason, 1989; Hughes, Redley, & Ring, 2011). This assumption is crucial when it comes to maintaining, strengthening, and expanding the informal social networks of people with PIMD. Future research

should focus on how these relationships are established, and under what circumstances, in order for professionals to be able to support the development of new relationships and thereby expand the informal social networks.

Despite the general consensus that relationships (and thereby informal social networks) of people with PIMD are possible and important, professionals rarely take active steps in this regard. It is quite possible that professionals simply do not know where or how to begin. Using a model to understand informal social networks may be helpful. The model developed by Baars, Uffing, and Dekkers (1990) divides an informal social network into different layers. The outer layer is the extensive network and contains all the people a person knows by face but not name. The middle layer is the nominal network and includes people a person knows (indirectly) and meets. The inner layer is the personal social network that comprises the direct, sustainable, and meaningful relationships in daily life. Usually, people move from the extensive network into the nominal network and finally into the personal network, which means that a relationship is formed. It seems that people with PIMD have a rather small inner layer, comprised mostly of family, and scarcely any other members (see Chapters 2 and 4). Furthermore, the majority of the group members (from day-services setting or the living unit) of people with PIMD appear to be found within the extensive network, where hardly any interactions were observed (see Chapter 5). According to the professionals, the extensive network scarcely contains any people from outside the living unit, because people with PIMD do not get out of their homes much (see Chapter 6). Considering that professionals mainly try to expand the informal social network of people with PIMD by including volunteers, meaning people who are not even part of the extensive network, there is little chance of success. It would be desirable for every layer to consist of at least a few people. This means that being present in society is already a way of working on expanding the informal social network: "Knowing someone's face" can be seen as a first step towards forming informal social relationships. This works in two directions, as other people get to know the "face" of the person with PIMD as well. A subsequent step might be to try moving a person from the extensive network to the nominal network. Finally, a person from the nominal network could then become part of the personal network. Future research should first focus on the personal network itself: What do they consider to be the impeding factors preventing them from maintaining the relationship with the person with PIMD and what are the facilitating factors? In line with this reasoning, people from the nominal network and extensive network should also be included in future research.

The principle of extensive, nominal, and personal networks can also be applied to contacts with group members. Since all group members naturally form a part of the extensive network, becoming a part of the nominal network should be a

first step towards achieving a relationship between a person with PIMD and a group member. Providing opportunities for interaction paves the way towards moving to a more inner layer of the network. Future research into relationships between people with PIMD and their group members should take into account the opportunities provided for people with PIMD to interact.

7.4. Practical implications

The current study shows that support is needed to enhance the informal social networks of people with PIMD. However, interventions designed to support this for people with PIMD are scarcely available. For people with intellectual disabilities, there are multiple interventions for enhancing informal social networks available. These interventions cannot, however, simply be applied in support of people with PIMD because of their specific characteristics. Therefore, the interventions available need to be adapted. In the Netherlands, several interventions for enhancing the informal social networks of people with intellectual disabilities are available (see Kruijswijk et al., 2014, for a compilation). Roughly speaking, all these interventions follow similar steps: (1) mapping the network, (2) discussing the network, (3) taking active steps, and (4) evaluation. This routine can be intertwined with an Individualized Support Program for people with PIMD (Vlaskamp et al., 2015). As the name already suggests, this program is tailored to individual wishes and needs. In this program, the following steps are taken: (1) setting up a personal profile, (2) defining a multi-disciplinary long-term goal for two years by all people involved (family and professionals), (3) defining the main goals for a period of one year in order to reach the long-term goal and to execute monodisciplinary short-term goals for a period of 4-6 weeks, and (4) evaluation of the outcomes (Vlaskamp et al., 2015).

Whereas the Individualized Support Program begins with setting up a personal profile, network interventions begin with mapping the networks. When mapping the social network of people without disabilities, or of people with intellectual disabilities, the person him/herself is the informant. Due to the severity of the disabilities of people with PIMD, they are not able to function as informants in a direct way. They need other people to do this for them. This needs to be done in close collaboration with parents, or other people from the personal network, and professionals, since both parties play an important role in the lives of people with PIMD (Jansen et al., 2013, Wibaut, Calis, & Van Gennep, 2006). Mapping the network is an important part of identifying problems and requires specific instruments. Commonly used instruments in general network mapping are a genogram (family tree), an ecogram (mapping friends, acquaintances, and formal support), or network circles (number of people in a network and their positions relative to the individual) (Smit & Van Gennep, 1999). Specifically for people with intellectual disabilities, the MSNA-ID (Maastricht Social Network Analysis for

People with Intellectual Disabilities, Van Asselt-Goverts et al., 2012) has been designed. Drawing up genograms (e.g., McGoldrick, Gerson, & Petry, 2008) and ecograms (e.g., Herman, 2012) can be a convenient method for professionals to get to know the background of the personal network and to work indirectly on strengthening the relationship between these two. Furthermore, genograms as well as ecograms are useful for revealing sources that might enhance the informal networks. In the support of people with PIMD, network mapping should be part of the personal profile (Vlaskamp et al., 2015).

In the Individualized Support Program, the personal profile forms the basis for determining the perspective for an individual with PIMD, and indicates the desired situation or advisable change (Vlaskamp & Van der Putten, 2009). When working with social networks, the map of the network always constitutes the starting point for further action. Discussing the network is an important second step, especially for people with PIMD. Since people with PIMD are not able to express their own wishes and needs concerning their social networks, others are needed to do so for them. For future action it is important that the personal network and the professionals reach some sort of consensus. In the discussion about the current network, different aspects should be discussed. In line with Van Asselt-Goverts et al. (2012), we would recommend discussing the size and composition of the network, the variety of its members, the accessibility of the members, and the structure of the relationships (frequency, initiative, length, basis, activities, and function). Per topic, the personal network and the professionals should discuss whether they find the current situation satisfactory and, if so, why. If the personal network and the professionals feel that the current network is unsatisfactory, two general needs can be distinguished: strengthening the existing network or expanding the network (Heaney & Israel, 2008; Smit & Van Gennep, 1999). The chosen direction should be tailored to the (assumed) wishes and needs of the individual with PIMD. The discussion should conclude with what the desirable situation is, according to all the people involved. Within the Individualized Support Program (Vlaskamp et al., 2015), this can be seen as a part of setting up the perspective, that is, what is believed to be important for this individual with PIMD.

When the desirable situation has been formulated, active steps can be taken. If the direction of strengthening the current network is chosen, it is possible to do this in different ways (Smit & Van Gennep, 1999): reanimating (refreshing faded contacts or giving predictable relationships a boost), activating (more effectively using the qualities of a network member or increasing the involvement between the two), unblocking (resolving disturbances in the network or resolving practical issues), intensifying (higher frequency of contact, contact in another situation, eliminating shallow contacts), and maintaining (keeping the network as

it is). These strategies are also useful for people with PIMD, if the disabilities of the people with PIMD are kept in mind. Furthermore, all previously named ways can also be applied when strengthening connections with group members.

Smit and Van Gennep (1999) provide multiple examples for when expansion of the network is desired. However, with regard to these examples it is important to keep some considerations in mind. First, all the people involved need to realize that it takes time to form a relationship and small steps are required, and so thinking in terms of inner and outer circles can be helpful. Second, it is important to make sure that the personal network and the professionals collaborate: The network is already small and therefore often under pressure; making members responsible for expanding the networks without the support of the professionals will increase the pressure and damage the network (Van Lanen & Claassens, 2012). Third, it is important to understand why expansion is desired: Is it for closer relationships, or is it to enable the person with PIMD to perform more activities? According to Wibaut et al., (2006) it is important for a (new) network member never to be assigned the tasks of a professional.

As well network interventions as the Individualized Support Program conclude by evaluating the steps taken and ascertaining in the end whether the desirable situation has been achieved. Wibaut et al. (2006) studied those effective factors found in network interventions with positive outcomes. These factors, among others, included individualized planning, working methodically with a clear goal and small steps, and structural integration into the organization. These factors, in turn, form the basis of the Individualized Support Program (Vlaskamp et al., 2015; Zijlstra, Vlaskamp, & Poppes, 2005). For future research it would be interesting to focus on the applicability and results of network interventions within the Individualized Support Program.

In sum, for people with PIMD it is definitely important to map the current social network in close collaboration between the personal network and the professional. Subsequently, this current network needs to be discussed and, based on the wishes and needs of the individual with PIMD, a desired situation should then be formulated. In order to achieve this desirable situation, it is important to set clear goals. These goals should then be translated into small steps leading to concrete action. This form of network intervention can be seamlessly integrated into the Individualized Support Program and thereby become a part of the daily support.

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Samenvatting

In dit proefschrift wordt onderzoek beschreven dat tot doel heeft om in beeld te brengen op welke manier de informele sociale netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen onderhouden of uitgebreid kunnen worden. Dit om uiteindelijk te komen tot een passende werkwijze om de informele sociale netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen te optimaliseren om op die manier bij te dragen aan een hogere kwaliteit van bestaan voor deze doelgroep.

Bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen is er naast een (zeer) ernstige verstandelijke beperking, sprake van een ernstige motorische beperking. Naast deze beperkingen is er vaak sprake van bijkomende problematiek, hierbij valt te denken aan sensorisch problemen (bijvoorbeeld met de visus of het gehoor), medische problematiek of problemen op het gebied van communicatie. Door de ernst en combinatie van de problemen is deze doelgroep in het dagelijkse leven bijna volledig afhankelijk van anderen, met name voor het onderhouden en uitbreiden van hun sociale netwerken.

Een sociaal netwerk bestaat uit alle mensen met wie er een relatie is, dit kunnen formele (vaak op basis van betaling, professionals) en informele (vanuit persoonlijk belang, familie, vrienden etc.) relaties zijn. Deze relaties kunnen meerdere functies hebben die grofweg te verdelen zijn in een praktische (informatie verschaffen, goederen en diensten bieden) en emotionele (geborgenheid, liefde, vertrouwen, zorg) functie. Vaak wordt gezien dat de mensen uit het formele netwerk voornamelijk praktische ondersteuning bieden terwijl mensen uit het informele netwerk overwegend emotionele ondersteuning bieden. Bij mensen met een (zeer) ernstige verstandelijke en meervoudige beperking lijkt, vanwege de hoge behoefte aan praktische ondersteuning, het hebben van een formeel netwerk vanzelfsprekend. Over het informele netwerk is echter weinig bekend, terwijl dit juist zo belangrijk is voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen: ze kunnen zorgen voor meer participatie, inclusie, dragen bij aan een betere gezondheid en voorkomen eenzaamheid. Kortom, sociale netwerken dragen bij aan de kwaliteit van bestaan voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen.

Mensen met verstandelijke beperkingen zonder verdere bijkomende beperkingen hebben kleine netwerken (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). Onderzoek bij de doelgroep mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen over dit onderwerp ontbreekt. Dit is merkwaardig, want vanwege

de ernst en combinatie van de beperkingen is de verwachting dat de netwerken bij deze doelgroep nog kleiner zijn dan die van mensen met verstandelijke beperkingen. Daar komt nog bij dat de doelgroep van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen juist zo afhankelijk is van anderen in het dagelijkse leven, zo zijn zij niet in staat om hun eigen informele sociale netwerken te onderhouden, laat staan uit te breiden. Om die reden is het van belang om een goed beeld te hebben van de huidige sociale netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Daarnaast moet in kaart gebracht worden wat er allemaal al gedaan wordt om de netwerken te onderhouden en uit te breiden en tot slot is het noodzakelijk om de visie van de professionals met betrekking tot de sociale contacten te onderzoeken.

Hoofdstuk één is een inleidend hoofdstuk waarin de context van het onderzoek en de onderzoeksvragen worden beschreven.

Hoofdstuk twee geeft een overzicht van de huidige structuur van de sociale netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Over 205 mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen (90 mannen, 115 vrouwen, gemiddelde leeftijd: 48, SD: 15.8) zijn direct betrokken professionals bevraagd over de sociale netwerken van deze mensen. Hen werd gevraagd met wie de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen het afgelopen jaar contact had, op welke manier en hoe vaak. Gemiddeld genomen hadden de mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen met 5.1 informele sociale contactpersonen contact (range: 0-26, SD: 4.2). Voor 72.7% van de mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen gold dat zij met één tot zes informele sociale contactpersonen per jaar contact hadden. Gekeken naar de informele sociale contactpersonen, had 58.2% van hen minder dan één keer per maand contact en 29.5% had slechts een of twee keer per jaar contact. In totaal 18.6% van alle contactpersonen had minstens eens per week contact. Van alle contactpersonen was 79.4% familie, waarbij ouders significant vaker contact hadden dan een ieder ander. Op visite komen was de meest gebruikte vorm van contact. Op basis van deze resultaten werd geconcludeerd dat de sociale netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen klein zijn en kleiner dan die van mensen met een verstandelijke beperking. Daarnaast werd geconcludeerd dat professionals, vanwege hun positie, een belangrijke rol kunnen spelen in deze sociale netwerken.

In *hoofdstuk drie* wordt besproken welke factoren gerelateerd zijn aan de structuur van de sociale netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Deze factoren zijn de leeftijd, de communicatieve mogelijkheden (lichaamsbeweging, gezichtsuitdrukking of oogbewegingen,

vocalisaties en symbolische communicatie), en de huidige woonsituatie (op een afgelegen terrein of een setting in de wijk). Het bleek dat alleen de leeftijd van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen negatief gerelateerd was aan zowel de grootte van het netwerk als de frequentie van de contacten. De huidige woonsituatie was uitsluitend gerelateerd aan de frequentie van de contacten. Op basis van deze resultaten wordt geconcludeerd dat het sociale netwerk van iemand met (zeer) ernstige verstandelijke en meervoudige beperkingen die op een instelling komt wonen vanaf dat moment niet meer wordt uitgebreid. De netwerken worden met het verstrijken van de jaren steeds kleiner en de intensiteit van het contact ook steeds lager. Het lijkt daarom van belang dat er al bij binnenkomst op een instelling ingezet wordt op het onderhouden en desnoods versterken van het bestaande netwerk.

In *hoofdstuk vier* wordt een exploratief onderzoek beschreven naar ongedwongen interacties tussen mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen en hun groepsgenoten. Het onderzoek kijkt specifiek naar de typen interacties die plaatsvinden in een vrije (ongecontroleerde) situatie en welke mogelijkheden de mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen door de begeleiders geboden kregen om te kunnen interacteren met groepsgenoten. In totaal zijn er 14 mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen geobserveerd (50% mannelijk, 50% vrouwelijk), met een gemiddelde leeftijd van 30.6 jaar (range: 4-53, SD=17.6). De observaties duurden drie aaneengesloten uren, waarbij iedere vijf minuten gescoord werd óf er sprake was van interactie, met wie die interactie plaatsvond en het type interactie. Daarnaast werd er een plattegrond van de groep getekend met alle posities, en werden alle verplaatsingen daarop weergegeven. Gemiddeld werden er 15.2 interacties per participant geobserveerd (range: 3-33, SD = 8.9) waarvan 5.1% met een groepsgenoot, 73.4% met een begeleider, 14.9% met de observator en 6.5% met overige personen (bijvoorbeeld een therapeut). Van de 14 geobserveerde mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen waren er vijf die met een groepsgenoot interacteerden. Het was bijna nooit mogelijk voor de participanten met (zeer) ernstige verstandelijke en meervoudige beperkingen om een groepsgenoot aan te raken. In 61.3% van de observaties was het onmogelijk om een groepsgenoot zowel zonder al te veel moeite aan te raken, dan wel te kunnen zien zonder al teveel moeite. Van de 10 geobserveerde interacties met groepsgenoten was het drie keer onmogelijk voor de participant om de interactiepartner te zien of aan te raken, deze interacties bestonden uitsluitend uit vocalisaties. Op basis van de beschreven resultaten wordt geconcludeerd dat, ondanks dat de situatie niet faciliterend is, mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen toch op zoek zijn naar interacties met hun groepsgenoten. Begeleiders zijn in staat om deze voorwaarden te optimaliseren, bijvoorbeeld door groepsgenoten vaker dicht bij

elkaar te zetten, om daarmee interacties tussen mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen en hun groepsgenoten te faciliteren

In *hoofdstuk vijf* wordt beschreven op welke wijze professionals trachten de informele sociale netwerken te onderhouden, te versterken en uit te breiden. Daarvoor werd de inhoud van 60 individuele ondersteuningsplannen geanalyseerd. Deze individuele ondersteuningsplannen zijn inductief gecodeerd en met behulp van quotes geïllustreerd. Het uiteindelijke codeerschema bestond uit drie hoofdcategorieën, 12 subcategorieën en in totaal 45 codes. In alle individuele ondersteuningsplannen werden sociale contacten genoemd. In totaal zijn er 1340 quotes over sociale contacten gevonden, met een gemiddelde van 22.3 quotes per individueel ondersteuningsplan. De drie hoofdcategorieën waren: geschiedenis, huidige situatie en toekomstige situatie. In totaal ging 22.6% van alle quotes over de geschiedenis van de sociale contacten en werd dit in 93.3% van de individuele ondersteuningsplannen beschreven. De huidige situatie stond in alle plannen beschreven en 71.2% van alle quotes ging hierover. Van alle quotes ging slechts 6.2% over de toekomst en werd dit in 68.3% van de plannen beschreven. Sociale contacten in de toekomst gingen voornamelijk over wensen, waarbij de meest beschreven wens was om de situatie te houden zoals deze op het moment is. Minder dan 1% van alle quotes betrof concrete doelen op het gebied van sociale contacten. Op basis van de resultaten wordt geconcludeerd dat er meer aandacht moet komen voor sociale contacten van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Daarnaast is het belangrijk dat professionals de relevantie van sociale contacten voor deze doelgroep inzien.

Hoofdstuk zes beschrijft de houding van de professionals ten aanzien van persoonlijke netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Het persoonlijke netwerk betreft de langdurige en liefdevolle relaties die een onderdeel van het grotere sociale netwerk vormen. Het onderzoek kijkt specifiek naar het belang van persoonlijke netwerken voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen volgens professionals, en naar wat zij doen om de netwerken te onderhouden of uit te breiden en welke bevorderende en belemmerende factoren professionals daarbij ervaren. Dit hoofdstuk geeft een analyse van interviews die met in totaal 24 professionals gehouden zijn met als thema de persoonlijke netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Deze groep professionals had een gemiddelde leeftijd van 38.9 jaar (range: 23-63, SD = 10.6) en een gemiddeld aantal jaren werkervaring van 12.3 jaar (range: 1-37, SD = 8.9). In totaal zijn er 12 begeleiders van de woning, vijf begeleiders van de dagbesteding en zes orthopedagogen geïnterviewd. Alle interviews werden persoonlijk en individueel afgenomen door de onderzoeker, op geluidsband opgenomen en later verbatim uitgetypt. Deze transcripties werden gecodeerd op basis van

literatuur en inductieve codering. Het uiteindelijke codeerschema bestond uit vijf hoofdcategorieën en in totaal 45 codes. In totaal waren er 808 quotes gecodeerd en waar het soms mogelijk was om meerdere codes aan één quote te verbinden zijn er in totaal 871 codes gegeven. Het bleek dat alle professionals persoonlijke netwerken voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen van belang vonden, met name voor het gevoel ergens bij te horen en deelname aan de maatschappij. Het onderhouden of versterken van het persoonlijke netwerk gebeurde in 37.5% van de interviews niet of nauwelijks. De relatie tussen de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen en het persoonlijke netwerk werd op directe en indirecte manieren onderhouden of versterkt, bijvoorbeeld door het organiseren van activiteiten, mensen uitnodigen, kaartjes sturen of over de persoon met (zeer) ernstige verstandelijke en meervoudige beperkingen bellen met het persoonlijke netwerk. Het bewust uitbreiden van persoonlijke netwerken gebeurde volgens 58.3% van de geïnterviewde niet of nauwelijks. Wat er wel gebeurde was dat mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen op een wachtlijst gezet werden voor een vrijwilliger. In totaal werden er twee keer zo veel belemmerende factoren genoemd door professionals in vergelijking met bevorderende factoren. De kenmerken van de doelgroep werden door 95.8% van de participanten als belemmerend ervaren voor het werken aan persoonlijke netwerken. Ook het persoonlijke netwerk zelf en de maatschappij werden door veel mensen als belemmerend ervaren. Tegelijkertijd werden de kenmerken van de doelgroep ook als bevorderend ervaren, doordat het een groep is die zorg oproept en kleine gebaren al groot zijn. Wat professionals bevorderend vonden, waren duidelijke voorwaarden, zoals een goed vrijwilligersbeleid of een goede ligging van de faciliteiten ten opzichte van 'de maatschappij'. Het hoofdstuk sluit af met de conclusie dat er een nauwe samenwerking moet komen tussen het formele netwerk en het informele persoonlijke netwerk om op die manier de netwerken van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen te optimaliseren.

Dit proefschrift sluit af met *hoofdstuk zeven* waarin de discussie uiteengezet wordt. Ondanks dat zowel vanuit de praktijk als de wetenschap het belang van informele sociale netwerken wordt erkend, wordt er weinig aan gedaan om de huidige, schrale situatie te verbeteren. Door de netwerken in een bredere context te plaatsen, ontstaan er meer mogelijkheden om hier mee aan de slag te gaan. Netwerken kunnen gezien worden als cirkels, waar de binnenste cirkel voor het persoonlijke netwerk staat (de belangrijke relaties), de cirkel erbuiten voor het nominale netwerk (mensen die je kent en ontmoet) en de buitenste cirkel is het extensieve netwerk (mensen die je van gezicht kent). Het is hierbij belangrijk om te bedenken dat het doel is om mensen een cirkel naar binnen te krijgen, of allereerst in de buitenste cirkel te krijgen om vanuit daar meer naar binnen te

kunnen bewegen. Hiervoor is het allereerst belangrijk dat het netwerk in kaart gebracht wordt en dat beoordeeld wordt of en wat er nodig is om een netwerk te verbeteren. Zodra de richting bepaald is, kunnen er acties ondernomen worden. Het is in dit hele proces van belang dat de mensen uit het persoonlijke netwerk en de professionals nauw met elkaar samenwerken. De stappen die genomen worden om de netwerken te verbeteren kunnen naadloos ingepast worden in het ondersteunings- en opvoedingsprogramma voor mensen met EVMB.

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Summary

This dissertation describes research that provides information about the way informal networks of people with profound intellectual and multiple disabilities (PIMD) can be maintained or expanded. This should contribute to an intervention capable of optimizing the informal social networks of people with PIMD and thus of contributing to a better quality of life.

People with PIMD have profound intellectual as well as severe motor disabilities. In addition to these disabilities, there are sensory problems (for example, vision or hearing), medical problems, and problems with communication. Because of the severity and the combined impact of these problems, people with PIMD are almost completely dependent on others in their daily lives, and, by extension, for maintaining and expanding their social networks.

A social network consists of all those people one has a relationship with; these can be formal (often based on payment, professionals) and informal (based on personal interest, family, friends, etc.) relationships. These relationships can serve multiple purposes that can be roughly divided into practical (providing information, offering goods and services) and emotional (love, trust, care) ones. It is common for people from a formal network to offer mostly practical support, while people from the informal network mainly offer emotional support. Due to the high practical support needs of people with PIMD, a formal network is fairly self-evident. However, little is known about the informal network, even though this is just as important, or even more so, for people with PIMD: informal networks can contribute to participation, inclusion and better health, and can prevent loneliness. In sum, social networks contribute to the quality of life of people with PIMD.

People with only intellectual disabilities have small networks (Bigby, 2008; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts, 2016). Research about networks of people with PIMD is lacking. This is remarkable, because it is expected that, due to the severity and combination of the limitations, the networks of people with PIMD are even smaller than for people with only intellectual disabilities. In addition, people with PIMD are heavily dependent on others in their daily lives, meaning that they are not capable of maintaining, let alone expanding their own informal social networks. For that reason, it is important to have a clear impression of the current social networks of people with PIMD. Moreover what is done in order to maintain and expand the social networks should be clear. Finally, it is essential to look into the views and beliefs of professionals with regard to the social networks of people with PIMD.

Chapter One is an introductory chapter that describes the context of the research and the research questions.

Chapter Two provides an overview of the current structure of the social networks of people with PIMD. Professionals directly involved with 205 people with PIMD (90 male, 115 female, average age: 48, SD: 15.8) were questioned about the social networks of these people. They were asked with whom the person with PIMD had had contact in the past year, in what way, and how often. On average, people with PIMD had contact with 5.1 informal contact persons (range: 0-26, SD: 4.2). For 72.7% of the people with PIMD, it turned out that they had contact with one to six informal contact persons in the time span of a year. As for informal social contact persons, 58.2% of them had contact less than once a month and 29.5% had contact only once or twice per year. A total of 18.6% of all the contact persons had contact at least once a week. Of all the contact persons, 79.4% constituted family: Parents had significantly more contact compared to all other contact persons. Visiting was the most frequent form of contact. Based on these results it was concluded that the social networks of people with PIMD are small, and smaller than those of people with only intellectual disabilities. Furthermore, it was concluded that professionals, because of their position, can play an important role in these social networks.

Chapter Three discusses the factors that are related to the structure of the social networks of people with PIMD. These factors are age, communicative abilities (body movement, facial expression/eye movements, vocalizations, and symbolic communication) and their current living arrangements (campus-style setting or small community home). It turned out that only the age of people with PIMD was negatively related to both the size of the network as the frequency of the contacts. The current living arrangement was only related to the frequency of the contacts. Based on these results, it was concluded that the social network of a person with PIMD does not expand once a person comes to live in a facility. With time the networks only become smaller, and the intensity of the contact becomes lower. It seems to be of great importance that, when moving to a facility, attention is especially paid to maintaining and, if necessary, expanding the existing network.

Chapter Four describes explorative research about spontaneous interactions between people with PIMD. This chapter specifically studies the types of interactions that occur in a non-controlled situation and what opportunities people with PIMD are offered in order to interact with group members. A total of 14 people with PIMD were observed, all having an average age of 30.6 years (range: 4-53, SD: 17.6). They were observed for three consecutive hours, and every five minutes it was noted whether interaction occurred, with whom, and what type of interaction it was. In addition, a map was drawn of the group, showing all positions

and relocations. On average, a total of 15.2 interactions per participant were observed (range: 3-33, SD: 8.9): 5.1% of these were with a group member, 73.4% with a direct support person, 14.9% with the observer, and 6.5% with others (for example, a therapist). Of the 14 people with PIMD we observed, five interacted with a group member. It was almost never possible for participants with PIMD to touch a group member. In 61.3% of the observation periods, it was impossible to touch a group member without effort, or to see a group member without effort. We observed ten interactions between a person with PIMD and a group member. In three of these it was impossible for the participant to touch or see the interaction partner: These interactions consisted exclusively of vocalizations. Based on these results, it was concluded that, despite the situation not being facilitating, people with PIMD still need and seek interactions with their group members. Direct support persons are capable of optimizing the conditions, for example by placing group members nearer to each other in order to facilitate interactions between people with PIMD and their group members.

Chapter Five describes the ways professionals try to maintain, strengthen, and expand informal social networks. For that purpose, the content of 60 individual support plans was analyzed. These individual support plans were inductively coded and illustrated with quotes. The final coding scheme contained three main categories, 12 subcategories, and a total of 45 codes. Social contacts were mentioned in all individual support plans. A total of 1340 quotes about social contacts were found, with an average of 22.3 quotes per individual support plan. The three main categories are: history, current situation, and the future. A total of 22.6% of the quotes were about the history of the social contacts and were described in 93.3% of the individual support plans. The current situation was described in all individual support plans and covered 71.2% of the quotes. Of all quotes, only 6.2% were about the future and were described in 68.3% of the plans. Mention of social contacts in the future pertained mainly to what was hoped for; the strategy most often described was simply to maintain the current situation. Less than 1% of the quotes involved goals in the area of social contacts. Based on the results, our conclusion is that more attention needs to be paid to the social contacts of people with PIMD. In addition, it is important for professionals to realize why social contacts for people with PIMD are important.

Chapter Six is a description of the attitudes of professionals vis-à-vis the personal networks of people with PIMD. The personal network contains the long-term and loving relationships that are part of the larger social network. This study specifically examines the importance of personal networks for people with PIMD from the point of view of professionals, and what steps they are taking in order to maintain or expand networks, as well as the facilitating and impeding factors they have experienced in this regard. This chapter provides an analysis

of interviews that were held with 24 professionals about the topic of personal networks for people with PIMD. These professionals had an average age of 38.9 years (range: 23-63, SD: 10.6) and an average working experience of 12.3 years (range: 1-37, SD: 8.9). A total of 12 direct support persons from the living unit, five support persons from the day services setting, and six healthcare psychologists were interviewed. All interviews were individually conducted by the researcher and were voice-recorded. These recordings were transcribed and coded based on the literature and inductive coding. The final coding scheme consisted of five main categories and a total of 45 codes. A total of 808 quotes were coded; sometimes it was possible to assign more than one code to a quotation, therefore a total of 871 codes were assigned. It turned out that all professionals thought the personal networks of people with PIMD were important, especially for a sense of belonging and participation. Maintaining or strengthening the personal network did not occur or only barely occurred in 37.5% of the interviews. The relationship between the person with PIMD and the personal network was maintained or strengthened in direct and indirect ways, for instance by organizing activities, inviting people, sending postcards to or calling people in the personal network to give them information about the person with PIMD. According to 58.3% of the interviewees, consciously expanding the personal network never or hardly ever happened. Putting a person with PIMD on a waiting list for a volunteer did take place. Professionals indicated twice as many impeding factors as facilitating factors. The characteristics of the people with PIMD were experienced as impeding their working with personal networks by 95.8% of the participants. In addition, the personal network itself and society at large were experienced as limiting by a lot of the participants. At the same time, the characteristics of the target group were also experienced as facilitating, because what was involved was a group that evoked a sense of caring, and small things could be perceived as big. The policy for volunteers and the central location of the facility were also perceived as facilitating. The chapter concludes with the statement that close collaboration between the formal and informal network is necessary in order to optimize the informal personal networks of people with PIMD.

This dissertation concludes with *Chapter Seven*, the discussion. Despite the fact that the importance of informal social networks is widely acknowledged, little is being done to improve the current situation. By placing networks in a broader context, opportunities might arise to do so. Networks can be perceived as circles, with the inner circle representing the personal network (the most important relationships), with the circle outside that circle standing for the nominal network (people you know and meet) and the outer circle as the extensive network (people you know only by face). It is important to realize that the goal is to try and get people one circle closer to the inner one, or just into the outer circle and, from there, try to move them inwards.

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